Men's Experiences of Living with Parkinson's Disease

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Abstract

The goal of this thesis is to explore men's experiences of living with Parkinson's Disease, a progressive neurological disorder predominantly affecting men in older age. Research into PD has been predominantly informed by a biomedical, neurological model. Although bringing significant benefit to PD's treatment, this approach fails to adequately consider the question of PD's lived experience, leading to major gaps in our knowledge of the condition and its effects on sufferer's lives. In addition, although making up the majority of sufferers, the specific needs of older men with PD have been neglected within wider research into PD. Using a phenomenological methodology concerned with men's experience of the lifeworld, and how this experience is influenced by gender and ageing, this study used narrative interviews combined with a photographic elicitation approach to ascertain the lived experiences of 15 men, from a number of different areas and of differing ages.

The findings of this thesis indicate that PD is more than simply a movement disorder. Instead it should be understood as a condition which disrupts the unity of the body, self and world. PD brings about particular challenges to men's experience of the lived body and lived time, distancing them from a shared experience of the lifeworld. Men also found ways to try and cope with their PD, but these approaches had to continually change as men moved through the illness. Finally, men's lived experience was intertwined with ageing and masculinity. PD posed a threat to men's masculine status; however men could also use masculinity as a resource to understand PD's various effects on their lives. How well men could respond to these changes had key implications for their continued well-being and quality of life, therefore giving insights into how future PD services can be improved.

This thesis concludes by making recommendations for the development of person and gender sensitive services in PD. These include paying greater attention to PD's lived experience and the stories men tell of their illness; engaging with the problems men identify that PD causes in their lives; and the greater provision of forms of information and psychosocial support which recognises all of PD's effects; including non-motor symptoms, psychosocial consequences and medication induced side effects.

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This thesis is dedicated to the memory of Dr Andrea Litva, one of my original supervisors before her tragic and untimely death in 2009.

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List of Acronyms

APPGPD	All Party Parliamentary Group on Parkinson's Disease
BNIM	Biographic Narrative Interview Methodology
DoH	Department of Health
GMS	Geriatric Mental State Examination
MMSE	Mini Mental State Examination
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NSF	National Service Framework
PD	Parkinson's Disease
PROMS-PD	Prospective Study of Mood States in Parkinson's Disease
QoL	Quality of Life
UPDRS	Unified Parkinson's Disease Rating Scale

Chapter 1. Introduction

Introduction; The challenges of Parkinson's Disease

In this thesis I investigate men's experiences of living with Parkinson's disease (hereafter PD); a progressive neurological illness common in old age which frequently leads to severe disability. Using the philosophical and methodological standpoint of phenomenology, I examine the experiences of living with PD of fifteen men of varying ages, the difficulties it brought to their lives and how they responded to these problems. Drawing upon perspectives from gerontology, sociology and critical men's health, I also discuss how men's experiences of PD were influenced by masculinity and ageing; their position in social life as men and as older people. Finally, I explore how the insights gained from an appreciation of men's lived experience of PD can be used to inform service delivery and clinical practice in PD. In this introductory chapter I set the scene for my wider thesis. First I provide a brief summary of the background and goals of the thesis. Following this, I give a brief background to PD; its aetiology, epidemiology and symptoms, and its treatments. I then conclude by giving an overview of the thesis and its structure.

Part 1. Background to the research

A neurological illness predominantly occurring in older age, PD leads to a progressive loss of motor function leading to physical disability (Duviosin & Sage 2001). PD's effects on movement are well known, but as our knowledge of its neurological basis and epidemiological effects has improved increased attention is being paid to PD's wider effects, including non-motor symptoms and quality of life (Schrag 2006; Duncan *et al* 2012). Alongside motor symptoms dementia, depression, anxiety, hallucinations, impulse control disorders and psychosis have all been found to be common in PD

(Poewe 2008; Gibson *et al* 2012; Weintraub *et al* 2013). Recognition of these wider symptoms has also led to questions about their relative impacts; for example on well-being and quality of life (e.g. Abudi *et al* 1997; Schrag 2006; Rahman *et al* 2008). This work has shown significant discrepancies between patients and clinicians expectations of the illness experience, raising questions about how far PD's medical treatment meets sufferers own concerns (Stanley-Hermanns & Engbretson 2010). Further questions can also be asked, such as how sufferers experience PD's various symptoms and how they try to cope with their PD (Toombs 1988; Habermann 1996). However with a few notable exceptions discussed later in this thesis, research into PD has not yet adequately answered these questions. As a consequence, although we know much about the biology and neurology behind PD (although clearly not enough), our knowledge of PD as a lived condition remains limited, a gap with numerous implications for PD's treatment and care (Solimeo 2009; Haahr *et al* 2010).

Given the paucity of studies examining sufferer's experiences of living with PD, it is this area that my thesis hopes to make a contribution. Taking a cross-disciplinary perspective drawing on work within the medical and health sciences alongside the approaches of medical sociology, social gerontology and critical men's health, I explore how a group of fifteen men with PD experienced, negotiated and made sense of their illness. Medical sociology and social gerontology have not yet turned their attention to PD. However these two perspectives have much to contribute to our knowledge of PD, in particular as an illness located within wider social life. PD has a biological reality, the loss of dopamine leading to physiological effects (Haaxma *et al* 2007). But it also has a subjective, 'lived' experience, which importantly is underpinned by a variety of social practices. The practices I pay greatest attention to in this thesis are gender and its intersection with ageing (Calasanti & Slevin 2006; Solimeo 2008; 2009). As scholars

concerned with the experience of illness and their relation to medical practices we occupy a privileged position, able to bridge the clinical worlds of medicine and the experiential worlds of sufferers. I therefore hope to give insights into how PD's experience is positioned within the complex structures and practices determining older men's lives (Higgs & Rees Jones 2009).

The goal of this thesis is therefore to explore PD's everyday 'lived' experience. My starting point is phenomenology; the study of experience as it presents to consciousness (Schutz 1967; Benner 1994; Dowling 2007). We usually experience much of our everyday lives in a taken for granted manner; it is simply there, our practices and acts hidden to our conscious thought (Leder 1990; Benner 1995). Many of these are located in our bodies; how we use our bodies to fulfil our everyday projects. But Illness has the power to bring the body, and the various everyday practices underpinning the body's place within the natural attitude into relief, revealing its structure as the body begins to break down (Leder 1990). Through this approach I hope to examine PD's consequences for men's everyday lives, the resources they use in responding to these problems, and how these resources are related to wider forms of social practice. These questions are useful for theory but they also have important practical implications. Not least through attending to PD's lived experience we can develop health services which can attend to sufferers concerns and ultimately can help them to negotiate their disrupted lives (Stanley-Hermanns & Engbretson 2010).

Part 2; Parkinson's Disease: an overview

First it is first useful to provide an overview of PD; what PD is as defined by medical knowledge. Historically considered a movement disorder, developments in both neuroscience and epidemiology have led to significant improvements in our knowledge

of PD's underlying aetiology, epidemiological characteristics and symptom profile (Moriera & Palladino 2005; Solimeo 2009). However questions remain about how far this conceptualisation has filtered through to routine clinical practice (Playfer 2007; APPGPD 2009; Parkinson's UK 2011). Given that a biomedical model of PD provides the basis for how sufferers themselves understand their illness, it is worth exploring medicine's account of PD and its various symptoms (Solimeo 2009). In this section I therefore provide a brief description of PD; its major motor and non-motor symptoms, its aetiology and epidemiology and its current forms of treatment.

Pathology, Aetiology and Epidemiology

PD's pathology is the consequence of the loss of striatal dopamine within the Substantia Nigra region of the brain, where it is responsible for motor functioning (Duviosin & Sage 2001; Playfer & Hindle 2008). After Alzheimer's disease PD is the second most common neurological disorder, affecting between 120000 and 127000 people in the UK (Caap-Ahlgren *et al* 2002; von Campenhausen *et al* 2005; Parkinson's UK 2012). Despite numerous attempts to identify its causes, PD's underlying aetiology remains unknown. Although a number of genetic and environmental factors have been associated with PD, including exposure to certain chemicals or metals, genetics or blows to the head, increasing age is the only risk factor which is consistently associated with PD (Playfer & Hindle 2008; Weintraub *et al* 2008a; Hindle 2010). It is likely that PD's origins will be due to a number of these factors, however as yet knowledge of the causal mechanisms leading to PD remains out of reach.

PD has been described as an exemplar illness of older age (Hindle 2010). Symptoms usually begin after 50 with average age of onset being around 60 years. Given that life expectancies are only slightly reduced by PD, most sufferers can therefore expect to

live with the illness for many years, even decades (Ishihara *et al* 2007). PD predominantly affects older people, however approximately 10% of sufferers have young onset PD, where symptoms present below 40 years of age (Schrag *et al* 1998; Calne & Kumar 2008). Those with young onset PD are less likely to face cognitive impairment when compared to those in older age, but are more likely to experience motor fluctuations, mood disorder and poorer quality of life (Schrag *et al* 1998). In addition, young onset PD sufferers and older onset sufferers are likely to experience a different set of demands for example remaining in employment, raising a family or being retired (Schrag & Banks 2006). These demographic differences, in which the majority are in older age but a significant minority are younger gives rise to questions about how far current services are able to meet the needs of these different groups (Solimeo 2008).

Although there is less consensus when compared to age, there is also evidence to support the claim that PD disproportionately affects men. Prevalence rates have been shown to be between 1.5-2 times higher in men (Van Den Eeden *et al* 2003; Ebadi & Pfeiffer 2005; De Lau & Breteler 2006; Haaxma *et al* 2007). Men are also more likely to develop the disease at a younger age and experience a more severe disease type (Abudi *et al* 1997; Haaxma *et al* 2007). Such sex differences raise questions about how PD's experience differs according to gender; the social characteristics attributed to biological sex (Connell 1995; Solimeo 2008). Older men are a group whose needs have seen little consideration within routine clinical practice. Indeed within the burgeoning work on masculinity and men's health older men have seen little concern (Arber *et al* 2003; Calasanti 2004; Calasanti & Slevin 2006; Meadows & Davidson 2006; Bennett 2007; Thompson 2008). Given these issues, as an illness predominantly affecting older

men PD gives us an as yet under-examined opportunity to examine how older men experience chronic illness and the various resources they use in doing so.

Signs & Symptoms.

PD's motor symptoms continue to receive greatest attention within medical research and clinical practice (Weintraub *et al* 2008a). PD has four 'cardinal' motor symptoms; Tremor, Rigidity, Akinesia/Bradykinesia and Postural Instability (Jankovic 2008).

Tremor. Tremor; a rhythmic shaking usually in the hands, arms or legs is the most publicly recognisable symptom of PD (Weintraub *et al* 2008b; Jankovic 2008; Parkinson's UK 2012). Tremor typically starts in one side of the body, and will disappear if the limb is moved. In time tremor will increase in severity, frequency, eventually affecting both sides of the body. For many tremor will be the most visible symptom of their PD and can therefore be acutely embarrassing and distressing, and for some even potentially stigmatising (Nijhof 1995; Duviosin & Sage 2001; Rahman *et al* 2008). However tremor also usually responds well to pharmacological treatment and for most will only have relatively minor effects on quality of life (Jankovic 2008).

Muscular Rigidity. Muscular rigidity; a resistance to the body's passive movements is found in many of the major joints of the body (Duviosin & Sage 2001). Rigidity manifests through difficulties in walking, through stiffness, through an often overwhelming fatigue and through muscle soreness or cramping. Dextrous hand movements also become difficult and may eventually become impossible (Van Gemmert *et al* 1999). Rigidity also leads to the characteristic blank, 'masked face' symbolic of PD (Mott *et al* 2004; Bowers *et al* 2006), to loss of the swallowing reflex, to drooling (Miller *et al* 2006) and to both faecal/urinary incontinence and chronic constipation (Rahman *et al* 2008). Muscle rigidity can therefore lead to a range of

problems with often significant consequences for sufferers' abilities or for their quality of life.

Akinesia /Bradykinesia. Akinesia; a general slowness and poverty in movement are the most common symptoms of PD (Caap-Ahlgren *et al* 2002). Movements slow in a way that cannot be accounted for by either muscle rigidity or general ageing. Akinesia also goes beyond movement to affect speech, thought and emotion. Many can find that *'everything becomes an effort'*, with even everyday activities requiring often overwhelming amounts of physical and mental exertion (Duviosin & Sage 2001; Bhatia & Gupta 2003; Benharoch & Wiseman 2004; Van Der Bruggen & Widdershoven 2005). Because of Akinesia, the pace of the world slows, meaning the everyday demands of life become harder and harder for men to manage; an experience with severe effects for well-being (Haahr *et al* 2010).

Postural instability. As PD progresses over time many sufferers will experience problems with their balance. Walking becomes more difficult as a stooped posture and a hesitant, shuffling gait develops, leading to a greater risk of falling (Roberts & Overstall 2008). Sufferers also frequently experience freezing, a motor block in which sufferers find themselves momentarily stuck, 'frozen' to the ground, itself frequently leading to falls (Macht & Ellgring 1999). Postural instability is usually uncommon in early PD, meaning that the onset of falls is often regarded as a threshold event, beyond which sufferers can expect to face greater levels of disability (Shulman *et al* 2008).

Non-motor symptoms.

Although still under-treated, increasing attention is being paid to PD's non motor symptoms (Leentjens 2004; Playfer 2007; APPGPD 2009). Cognitive impairment affects between 24% and 31% of older onset sufferers (DSM 2000; Aarsland *et al* 2005).

Impulse control disorders including hypersexuality and compulsive gambling have also been associated with PD, affecting approximately 15-20% of people on PD drug therapy (Crockford *et al* 2008; Wu *et al* 2009; Parkinson's UK 2012b; Weintraub *et al* 2013). Other common non-motor problems in PD include hallucinations and psychosis (Barnes & David 2001; Goetz *et al* 2006; Rabey 2009; Gibson *et al* 2012), sleeping problems (Poewe 2008), loss of sexual desire/function (Schartau *et al* 2003), excessive sweating, loss of appetite and loss of smell (Andersson & Sidenvall 2001). All of these can have significant negative effects on quality of life.

Of all of PD's non motor symptoms, mood disorders have arguably received greatest attention (Leentjens & Verhey 2002). Prevalence rates for depression in PD vary considerably; from 7% to 76% of sufferers, but average at approximately 40% (Slaughter *et al* 2001; Veazey *et al* 2005). Anxiety can be a more common problem than depression, even though it has seen less study (Weintraub *et al* 2008c; Brown *et al* 2011). Despite their prevalence, our knowledge about how to best treat mood disorders in PD remains limited (NICE 2006). The effectiveness of most antidepressant therapies, including both drug based therapies and psychological interventions are largely unproven in PD (Frisina *et al* 2009). As a result, despite the increasing acknowledgement of the significance of non-motor symptoms, medicine's ability to treat them remains limited, indicating an important avenue for further research (NICE 2006).

Pharmacological & Non Pharmacological Treatments

There is currently no cure, nor are there any treatments that can slow or reverse PD's progression. However fortunately a wide range of therapies do exist for PD. Drugs remain the dominant form of therapy, with its cornerstone being levodopa (Duviosin &

Sage 2001; Schapira *et al* 2009; Van Der Marck *et al* 2009). Levodopa operates by 'flooding' the brain with an artificial form of dopamine, leading to sustained improvements which assuming treatment continues will usually last several years. Other medications are also used either as initial therapies in milder disease, or to 'boost' the function of levodopa later in the illness. However these treatments cannot slow, stop or reverse PD's progression, all they can do is mask PD's major symptoms, with symptoms eventually 'overtaking' their effectiveness. To mitigate this, dosages will rise and new medications be added. However this will create further, significant demands for sufferers. In particular, eventually levodopa therapy causes a number of side effects, including confusion, hallucinations, psychosis and impulse control disorder (Onofrj *et al* 2006; Playfer 2007; Wu *et al* 2009; Gibson *et al* 2012; Weintraub *et al* 2013). Most significantly long term levodopa therapy will lead to motor fluctuations, the most well-known being dyskinesia; a series of involuntary tics, jerks, spasms or kicks; and off periods, a sudden and unpredictable loss of drug benefit and rapid return of symptoms (Matson 2002). These side effects are routinely judged to be one of the most distressing aspects of PD, leading to questions about how medicine responds to problems with their origins in PD's treatment (Schrag & Quinn 2000; Matson 2002; Rahman *et al* 2008).

Drugs are the major part of PD's treatment, however guidance for the treatment of PD also recommends a number of non-pharmacological therapies in PD, including physiotherapy, speech and language therapy, occupational therapy and psychological and psychosocial interventions (NICE 2006; Van Der Marck 2009). The goal of non-pharmacological therapies in PD is to support the function of medications, to minimise the impact of disease symptoms, to help PD sufferers with their activities of daily living, and to provide information and support about PD (Van Der Marck 2009; Axelrod *et al*

2010). Currently the evidence base for many of these allied therapies is small but significant, leading to their growing role in PD services. However there remain gaps in the provision of these services, indicating that although recommended in PD guidance, multidisciplinary care has not yet filtered through into routine PD care (APPGPD 2009; Van Der Marck *et al* 2009).

Summary - PD as a complex condition

PD remains a complex and mysterious illness; one which remains difficult to effectively treat (Stanley-Hermanns & Engbretson 2010). A biomedical, neurological model of PD has proved dominant, with relatively little interest currently being paid to PD from outside of the medical sciences. Our scientific and neurological knowledge has led to dramatic improvements in our knowledge of PD, its core symptoms and how it can be treated. But significant gaps in our knowledge still remain. We still know little about its risk factors and of course how to 'cure' PD; to slow or reverse its progression. Furthermore we also know relatively little about PD's non-motor symptoms, and have only a poor evidence base about how to best treat them (Playfer 2007; Lemke 2008). As a result when compared to our medical knowledge of PD, there remain significant gaps in our knowledge of PD as a lived condition (Solimeo 2009; Stanley-Hermanns & Engbretson 2010).

These gaps have direct relevance for PD's treatment. Not least, as Abudi *et al* (1997) and Rahman *et al* (2008) have demonstrated, there are major discrepancies between what clinician's judge as important and sufferers own experiences. A wider range of issues are also salient. For example PD's symptoms although physiologically similar are felt differently by different social groups, including by men and women (Solimeo 2008). Given that little attention has been paid to these problems within clinical research into

PD, our knowledge of how different groups of PD sufferers experience these problems is extremely limited. Not least older men, the main group affected by PD have had little attention being paid to their specific experiences and needs. There is therefore an important need for research which goes beyond medical models to investigate PD's subjective experience. By doing so, we can pay better attention to the lived realities of PD sufferers, their needs and concerns, leading to better care. It is in this current gap in our knowledge of PD that I hope this thesis will make a contribution.

Part 3. Structure of the thesis

The goal of this thesis is to explore men's experiences of living with PD, how these experiences are influenced by both gender and ageing, and their implications for the delivery of PD care. To do this the thesis adopts the following structure. In chapter two I review the relevant bodies of literature pertaining to PD and its subjective experience and how this knowledge can be improved by engaging with issues of gender and ageing. In chapter three I discuss my research methodology and methods. My key theoretical standpoints are phenomenology and the phenomenological lifeworld, their role in how individuals make sense of lived experience, and men's use of narrative; telling stories about their condition in order to make meaning (Kleinman 1988; Toombs 1988; 2002; Van Manen 1990). I then discuss my choice of research methods, combining the deep personal engagement of narrative interviewing with a photo elicitation exercise encouraging men to reflect on their experiences (Oliffe & Bottorff 2007). Finally, I discuss the various ethical and reflexive dimensions arising from this study.

I then move on to the findings of this study. I begin in chapter four with a series of biographical descriptions for each of the men taking part in this study. In chapter five I

begin my account of the findings of this study by examining PD's effects on the phenomenological lived body (Toombs 1988). The changing lived body is at the centre of many of the problems of PD. In PD men are forced to attend to their bodies in new and increasingly alien ways, to 'feel' their bodies, and to experience the body as presence in their worlds visible to others and to the self. This changing experience of the lived body transforms almost all elements of sufferer's lives. In chapter six I discuss PD's effects on the experience of lived time (Toombs 1990; Ricoeur 1980; Del Vecchio Good *et al* 1994). The patterns around which our everyday experience of time is organised all change as new, strange forms of organising time rise to prominence. Furthermore, the experience of biographical, narrative time, of a present understood through a biographical past and an anticipated future also changes in PD, bringing wholly new ways of experiencing lived time (Ricoeur 1980; Munro & Belova 2008). The lived body, and lived time are therefore central to the changing experience of the lifeworld in PD; prioritised throughout men's accounts of PD and its effects on their lives.

In chapter seven I move on to explore how men respond to their PD. All the men had to learn how to live within a changing body and a changing lifeworld. In this chapter I focus on how men accomplished this, trying to cope with PD through their everyday acts, through these acts finding new ways to live within the lifeworld. Through men's acts and the stories they told of them, men could find new ways to cope, to incorporate PD into a changing biographical self. Gender and ageing are discussed throughout my thesis, but in chapter eight I bring these two social practices to the foreground. PD threatened a progressive, age based emasculation; eroding men's status in the world as men. But masculinity also becomes a key resource through which men make sense of their illness, re-appropriating, reinforcing or resisting specific

masculine gender practices when talking about their PD. And when men talked about gender, they also talked about age (Calasanti & Slevin 2006; Calasanti 2010). Through both they tried to make sense of their PD and their changing status in the world as men. Through an examination of the role ageing and gender play in shaping men's lived experience, we can see the role that social practices and relations play in how we make sense of illness.

I conclude the thesis in chapter nine by discussing the implications that the subjective, lived experiences discussed in this thesis have for current PD services. By paying attention to PD's lived experience and how it is situated within men's social lives and social worlds, we gain insights into how to best provide care that can meet the needs of men with PD. Finally, I bring this thesis to a close by reflecting on its conduct, its limitations, and how further qualitative, sociological and gerontological research can improve our knowledge of PD.

Chapter 2. Literature Review

Introduction: the problems of PD's treatment

In July 2009 the UK all Party Parliamentary Group for Parkinson's Disease published a report examining the quality of PD services in the United Kingdom. This report revealed numerous inequalities in PD care (APPGPD 2009). Problems include shortfalls in access to PD specialist staff; poor access to non-pharmacological therapies; geographical rationing of services; poor availability of information, counselling and psychological support services; a lack of recognition about the role palliative care can play; poor professional knowledge; little integration with other services and a general lack of leadership in service delivery (APPGPD 2009; McLaughlin *et al* 2011). These findings have been supported by a number of later evaluations and service audits reporting similar findings (e.g. Aragon & Kings 2010; Parkinson's UK 2010; 2011). In combination these reports paint a picture of services which currently fail to address many of the problems PD sufferers face.

The problems described above all indicate significant issues for the delivery of PD services. Although bringing significant benefits questions can be raised about how well these services meet PD sufferers' wider needs (Playfer 2007; Sunvisson *et al* 2009). In addition PD's symptoms and indeed its treatment place a number of demands on sufferers about which we currently know surprisingly little (Bramley & Eatough 2005). The consequences of this lack of attention to the wider experience of PD can be seen in many of the gaps in current service provision described above. In order to improve our knowledge of PD, and therefore to improve PD care, we need to ask wider questions about PD; including how is PD experienced by sufferers within the context of their everyday lives? What are the challenges they face, rather than what medicine thinks

they face (Abudi *et al* 1997; Brod *et al* 1998; Rahman *et al* 2008). How is the 'lived' experience of PD influenced by wider social issues, structures and practices? Finally, how can PD's routine care best address these problems as they are 'lived', situated within sufferers everyday lives? To set the scene for my wider thesis, in this review I discuss the current research literature investigating PD's subjective, lived experience, what has been done so far to address these questions, and the key gaps in our knowledge. In doing so I provide an evidence base, used here to support this thesis and its approach to PD.

Review Methodology

Given the trans-disciplinary nature of this thesis I used a wide ranging, comprehensive literature searching strategy to review the existing literature on PD. I searched a medical literature across a number of disciplines including neurology, movement disorders, geriatric medicine, psychiatry and epidemiology. In addition I searched clinical guidelines, service audits and the wider health policy literature on PD. I also explored the literature on PD within the nursing sciences and allied health professions. Finally I reviewed a number of literatures on chronic illness and ageing, gender and illness within social gerontology, medical sociology and the related social sciences, and sub-disciplinary studies of men's health. Literature searches were regularly updated throughout the period of study. Literature was sourced from several databases including Pubmed, Scopus, PsychInfo, Embase, the web of knowledge and Google Scholar using the following search terms; *Parkinson's Disease, Epidemiology, Aetiology, Phenomenology, Sex, Gender, Masculinity, Men, Ageing, Old Age, Older Age, Elderly, Young onset, Chronic Illness, lifeworld, lived experience.* I also used variations of these searches and associated MeSH terms. Hand searching of selected journals relating to PD, men's health and gerontology was also conducted. Any relevant papers were then

categorised into a series of thematic areas using endnote bibliographic databases. These themes came to provide a structure to this review, and included clinical studies of PD, studies of PD's lived/social experience, illness and embodiment, and illness, ageing and gender.

Organisation of literature review

I divide this review into three sections, each one dealing with a different area of the literature. In part one I discuss PD's subjective experience in relation to medicine, medical research and medical practice. I focus on two areas directly relevant to this thesis. First I consider the contemporary UK health care policy landscape relating to PD (NICE 2006; Playfer 2007; Parkinson's UK 2010; 2011). I then explore the growing epidemiological and wider literature applying Quality of Life approaches to PD. These two literatures set the scene for my wider argument by showing up a number of important differences between routine clinical practice, public health policy and sufferer's experiences.

In part two I discuss the work exploring PD's subjective 'lived' experience. A small body of literature predominantly found within nursing and the health sciences has led to important insights about PD's lived experience. This work can also be taken further by engaging with a wider literature within the social sciences. I also show how PD's lived experiences are also reflections of wider social and cultural practices. So far this work has not yet reached a critical mass, however a few studies have demonstrated how wider sociological and anthropological approaches can improve our knowledge of PD as a lived condition (Nijhof 1995; 1996; Solimeo 2008; 2009; Stanley-Hermanns & Engbretson 2010).

In part three I broaden this scope of this review to examine two perspectives within the social sciences and how they might usefully be applied to PD; the study of older age within social gerontology (Minkler & Estes 1999; Phillipson 2005; Calasanti & Slevin 2006) and the growing literature exploring masculinity, health and illness (e.g. Connell 1995; Robertson 2007; Emslie & Hunt 2009). Although these two perspectives have largely failed to engage with each other, a small gerontological literature has grown which considers ageing, gender and masculinity as intersecting processes (e.g. Arber *et al* 1995; 2003; Calasanti & Slevin 2006; Thompson 2006; Calasanti 2010). By drawing on examples using this intersecting perspective to examine older people's experience of illness, I explore how such an approach can be used to further our understanding of PD. I conclude this review by bringing these three literatures together. By paying greater attention to PD's subjective, lived experience and how this experience is situated within wider social practices, we can gain hitherto unstudied insights into the roles gender and ageing play in the experience of chronic illness in older age. More importantly, this knowledge can also provide specific insights about PD and its experience, with the potential to improve PD care.

Part 1. The literature on Public Health Policy and Quality of Life in PD

In this first section of my review I discuss two areas of the wider medical literature, what they tell us about PD and of greatest relevance, the gaps that they show up between current methods of service delivery and sufferers own experiences about the disease. First I consider current UK policies and guidance for the delivery of PD services and the differences between these recommendations and their implementation on the ground. I then discuss the literature on Health Related Quality of Life (QoL) in PD, a body of work which shows significant differences between biomedical, neurological approaches to PD and sufferers own interpretations. As a

result, clear gaps emerge within PD's routine treatment. When combined, these two literatures demonstrate that while bringing significant benefits current approaches to PD's treatment struggle to grasp many issues judged most important to sufferers. In order to grasp these issues, research into PD needs to engage with wider issues, including PD's lived experience (Stanley-Hermanns & Engbretson 2010).

UK Health Policy & PD

Within the UK PD service delivery is determined by National Institute for Health and Clinical Excellence (NICE) guidelines, which themselves draw on UK National Service Frameworks (NSF) for older people and for people with long term neurological conditions (NICE 2006; DoH 2001; 2005: Stewart 2007; Bernard *et al* 2008; DoH 2010). Together these guidelines promote an approach to PD in which services recognise both PD's motor and non-motor symptoms and seek to provide multidisciplinary care (NICE 2006; Ryton & Liddle 2009). However several years after publication the recommendations made by these guidelines have not been routinely implemented (APGPD 2009; Parkinson's UK 2010; 2011). A number of challenges to the provision of multidisciplinary services have been identified (Stewart 2007; APPGPD 2009; Parkinson's UK 2010; 2011). Services remain subject to regional variations. Drug therapies continue to dominate PD's routine treatment (Playfer 2007; Stanley-Hermanns & Engbretson 2010). Provision of non-pharmacological therapies including physiotherapy, speech and language therapy, psychosocial therapies and neurosurgery is seen as having a major role in PD's treatment, but their availability is generally patchy (Hurwitz *et al* 2005; Meadowcroft 2008; APPGPD 2009; Axelrod *et al* 2010; Parkinson's UK 2010; 2011). PD's routine treatment is often delivered across numerous specialties such as neurology, movement disorders, geriatric medicine and specialist PD services. However as discussed by Playfer (2007), and shown in Parkinson's UK's

(2010; 2011) annual regional audits of PD services, this can mean that differences in the provision of therapies can occur depending on the specialty in which care is provided. This means that PD care can often be fragmented; the full range of pharmacological and non-pharmacological treatments unavailable in many services.

There are also differences in the provision of wider therapies in PD, which either seek to treat non motor symptoms or provide assistance beyond the use of drugs. In a 2010 Parkinson's UK (2011) audit of PD services, only 38% of elderly care services and 11% of neurology services were routinely using existing tools to assess activities of daily living. Similar issues were found in the monitoring of non-motor symptoms, in which a high proportion of elderly care services (28%) and a majority of neurology services (54%) failed to routinely assess non motor symptoms (Parkinson's UK 2011). When compared to earlier audits these figures indicate that the situation was improving, however they still have some way to go (Parkinson's UK 2010). Other audits and studies of PD services have found similar problems; despite evidence for their effectiveness non drug interventions are often not routinely available, or conversely that such interventions are limited by a small evidence base (e.g. Gage & Storey 2004; Hurwitz *et al* 2005; Van Der Marck *et al* 2009; APPGPD 2009). Services such as speech and language therapy were often found to be unavailable in many areas of the UK, with two thirds of people in a study by Miller *et al* (2010) never receiving an assessment for speech problems (APPGPD 2009). We can therefore question how far current treatment models are able to meet the wider needs of many PD patients. Although guidelines recommend the treatment of PD as a 'whole system' disease affecting many aspects of a person's life, it is clear that in many services this has not been taking place (APPGPD 2009; Parkinson's UK 2011).

The failure of routine medical practice to treat PD as a 'whole system' illness has been shown most clearly in the treatment of mood disorders. Depression has been shown to affect approximately 40% of PD sufferers (Veazey *et al* 2005). Mood disorders are one of the most distressing elements of PD, often having greater impacts than motor symptoms (Rahman *et al* 2008; Brown *et al* 2011). However they remain routinely under-diagnosed within routine care (Schrag 2006; Schneider *et al* 2008). Furthermore despite the prevalence of mood disorders in PD little is known about how best to treat them (Leentjens 2004; Lemke 2008; Brown *et al* 2011). Anti-depressant drug treatments are routinely used to treat depression in PD despite having a poor evidence base; so far only a few clinical trials determining the effectiveness of anti-depressants in PD have taken place (Slaughter *et al* 2001; NICE 2006; Stewart 2007; Weintraub *et al* 2008b; Brown *et al* 2011). A few studies have supported the use of non-pharmacological treatments for depression in PD including cognitive behavioural therapy and counselling therapies (Dobkin *et al* 2007; 2008). However these therapies are only rarely offered within current practice (APPGPD 2009; Van Der Marck *et al* 2009).

In summary then these findings indicate both a relative lack of recognition for non-motor symptoms, which filters through into research into effective treatments, and implementation of services within routine clinical practice. Above all, it indicates a failure to adequately consider all the dimensions in which PD can affect sufferer's lives. The treatment of motor symptoms via drugs is prioritised, while PD's wider effects have seen less consideration, even when they have the potential to be deeply distressing. This situation is beginning to change. However the gap in research between motor and non-motor symptoms, and the gap between the provision of

multi-disciplinary therapies across all PD services indicates there is still some way to go before this is routinely achieved.

PD and Health Related Quality of Life

A further literature has also grown in recent years which apply the concept of health related quality of life (QoL) to PD. This literature has been concerned with the impact of diseases on issues beyond medical signs and symptoms, including psychological wellbeing and daily life (Rahman *et al* 2008). In addition a subset of work in this area has grown examining how people with PD seek to cope with their condition (De Ridder *et al* 1998; 2000; Montel *et al* 2009; Hurt *et al* 2011). Much of this work has also been concerned with the relative contributions PD's motor and non-motor symptoms make to QoL (Rahman *et al* 2008). However this work has also indicated a number of wider significant issues. Of most importance to this study, these studies have revealed important differences between clinician's judgements about the distress of PD's symptoms, and judgements made by patients themselves (Abudi *et al* 1997; Brod *et al* 1998). I now discuss the relevance of this literature and its findings to my study.

Perhaps unsurprisingly PD has been shown to have major negative impacts on QoL. What is more surprising is that it appears to have greater effects than illnesses with similar clinical measures of disability, for example arthritis or osteoporosis (Abudi *et al* 1997; Schrag 2006; Rahman *et al* 2008). Questions have also been asked about the relative contributions PD's motor and non-motor symptoms make to QoL. Rahman *et al* (2008), alongside Kuopio *et al* (2000), Schrag (2006) and Kleiner-Frisman *et al* (2010) show that many of PD's core motor symptoms; tremor, akinesia and rigidity have relatively minor effects on QoL. Rather it was the functional impairments caused by these symptoms, alongside, cognitive impairment, mood disorder, psychotic symptoms

and medication induced motor fluctuations that had greatest impact. Given that the goal of PD therapy is to alleviate motor symptoms, this work raises questions about how well pharmacological treatments reflect sufferers own experiences of the illness. The growing literature on quality of life in PD has made major contributions to the growing attention being paid to non-motor symptoms; what Rahman *et al* (2008) describes as a paradigm shift in how we think about PD. However as shown in the policy literature earlier, it appears that this shift is only slowly filtering through into routine clinical practice (APPGPD 2009).

In a second important finding of the literature on QoL in PD, PD sufferers also make significantly different judgements about their symptoms when compared to their clinicians (Abudi *et al* 1997; Brod 1998; Mott *et al* 2004; Dowding *et al* 2006; Rahman *et al* 2008). Abudi *et al* (1997) and Brod *et al* (1998) discovered that PD's motor symptoms were routinely judged more disabling by clinicians than by sufferers. Dowding *et al* (2006) report that depression and anxiety were routinely highlighted by patients as PD's most distressing symptoms, despite their receiving little attention in routine practice. The routine under-diagnosis of depression in PD is also complicated by later qualitative work by Tickle Degnen & Doyle Lyons (2004), who found that clinicians unfamiliar with PD could regularly judge PD patients as being more depressed than they actually were. In contrast sufferers judgements of the severity of medication induced motor fluctuations are greater than is routinely judged within clinical practice (Kuopio *et al* 2000; Rahman *et al* 2008). It can therefore be argued that two of the most distressing elements of PD, which can actually be caused by its medical treatment are routinely under-valued by clinicians when they make judgements about their patients quality of life. These findings further support the claim that in focusing on the

treatment of motor symptoms, those problems judged most distressing by sufferers do not receive sufficient attention within routine clinical practice.

Finally, the work on QoL in PD has indicated how different groups of sufferers also make differing judgements about their wellbeing. Age of onset has been associated with differences in QoL across a several physiological and social dimensions. Younger onset sufferers have been shown to have generally lower levels of QoL, to experience greater levels of perceived stigmatization, to have lower wellbeing, to experience a greater range of social and economic problems and to more frequently face motor fluctuations (Schrag *et al* 2003; Schrag & Banks 2006). These findings raise questions about how sufferers' age, their position in the lifecourse (for example work or family status) and their experiences of ageing influence their experience of PD. Gender has also been linked to differences in QoL, although differences in QoL between men and women have proved more variable. For example Moore *et al* (2005) and Haaxma *et al* (2007) have claimed that women have higher QoL in PD than men, not least because women appear to suffer from a more benign disease phenotype. However these findings have been disputed by other studies which suggest that women experience a poorer QoL (Kuopio *et al* 2000; Hariz *et al* 2003; Shulman 2007). Solimeo (2008) in a mixed methods study showed that men and women recorded similar levels of QoL according to quantitative assessment. However when examined qualitatively, the dimensions in which they reported problems with QoL differed greatly. Although the work on sex differences in QoL has not therefore reached a consensus this work, alongside the qualitative work of Solimeo (2008) indicates that gender; the social characteristics attributed to biological sex will have differing effects on QoL (Solimeo 2008). Based on these findings, the role that that gender, gender identity and gender relations play in judgements of PD warrants further study (Moore *et al* 2005).

Summary

The two literatures described above, evaluating PD services and determinants of QoL in PD show up several important issues in PD and its care. First, despite bringing numerous benefits a solely neurological, pharmacological approach to PD fails to resolve, or arguably even to consider many sufferers' wider therapeutic needs. Current models of service delivery fail to adequately address those symptoms sufferer's judge as being most distressing (Abudi *et al* 1997; Rahman *et al* 2008). In addition many clinicians routinely fail to fully understand PD from the perspective of their patients, seen in their differing judgements about the effects of PD's motor and non-motor symptoms. Clinicians judge PD's severity via symptoms which are of less importance to sufferers. But they can also routinely believe sufferer's well-being and QoL to be poorer than it actually is. Finally, they can also fail to pay attention to just how distressing many of PD's experiences can be, including those caused by medicine's treatment. Although prioritised within PD's pharmacological treatment motor symptoms are commonly less distressing than medication induced motor fluctuations, than emotional symptoms or than functional disabilities. This may be due to the fact drugs can improve these symptoms while non-motor symptoms remain much more resistant to treatment. However when examined through the literature auditing PD services, non-motor symptoms remain routinely under-treated within current PD services, so this is not simply the result of the effectiveness of pharmacological therapies (Parkinson's UK 2010; Brown *et al* 2011). Further gaps also exist in our knowledge of PD and quality of life; in particular differing judgements according to both gender and age (Moore *et al* 2005; Schrag 2006). The consequence of these differences is that clinical treatment priorities, based on what medicine can and cannot treat can diverge from patients lived concerns (Tickle-Degnen & Doyle Lyons 2004;

Doyle Lyons & Tickle Degnen 2003; Mott *et al* 2004). In addition, a universal approach to PD and QoL may miss important differences in the age or gender based experience of the disease; issues needing consideration is age or gender sensitive services are to be provided (Solimeo 2008).

Although coming from different perspectives Playfer (2007) and Sunvisson *et al* (2009) argue that many of these problems can be attributed to a neurological focus on PD's treatment. Although PD is most commonly treated within elderly care services, PD is not primarily treated as an illness of ageing (Parkinson's UK 2011). This neurological focus has undoubtedly had major benefits for our knowledge and treatment of PD. But in creating a particular way of knowing PD, it fails to consider the illness within its wider contexts (Schrag & Banks 2006; Solimeo 2008; 2009). However Sunvission *et al* (2009) argue that the gaps existing between patient experience and clinical practice, defined by a Cartesian, biomedical model of PD can be bridged. This can be achieved by paying greater attention to PD's subjective, lived experience. A small literature, based largely within the health and nursing sciences and using qualitative methodologies has sought to investigate this issue. I now turn my attention to these studies.

Part 2. The literature on PD's subjective experience

Sunvisson *et al* (2009) argue that seeing medicine's treatment of PD and its subjective experience as two distinct, disconnected paradigms within differing fields of study is unhelpful. Instead they can be brought together, promoting more attuned care in PD by encouraging a dialogue between these two paradigms. A small body of work has asked questions about PD's subjective experience. Much of this has been qualitative and phenomenological in character with the ultimate goal of improving care in PD by

paying careful attention to individual experience and personal meaning 'in all its social and personal complexity' (Bramley & Eatough 2005 p225). Although engaging with phenomenological approaches, this research has had an applied goal, seeking to improve PD care through a careful attunement to individual experiences and need.

The phenomenological character of this work brings a number of themes into relief, showing both the practical and existential impacts of PD. First and most importantly, this work understands PD not as a disease state made up of physiological signs and symptoms, each affecting specific body regions or movements. Instead PD is thought of as a condition affecting all elements of a sufferer's life, with impacts on the totality of the lifeworld (Phillips 2006; Van Der Bruggen & Widdershoven 2005; Sunvisson *et al* 2009). PD disrupts the unity of the mind, body, self and world (Haahr *et al* 2010). The body changes outwards; how men inhabit and act in the world. But it also changes inward, feeling 'different', experiencing new sensations and declining in its movements and abilities. Many of these studies have then considered the impact that PD has on the self; how sufferers continue to express themselves within the world, and ultimately, to find meaning in the world.

These studies have not just been concerned with PD's wider, existential experience. The experiences described above are also rooted within the practical activities of everyday life; the world brought into relief through our mundane, practical and habitual activities (Dyck 1995; Charmaz 2002). Charmaz (2002) argues that the self is built upon our everyday, taken for granted activities, meaning that as these daily habits break down, the self will become disrupted. From the phenomenological studies discussed here this certainly appears to occur in PD. In PD everyday life and the various activities upon which it is based becomes increasingly uncertain (Nijhof 1996; Bramley & Eatough 2005; Van Der Bruggen & Widdershoven 2005; Haahr *et al* 2010; 2011).

Habermann (1996; 1999) discusses how uncertainty and learning to live with uncertainty becomes a demand many people with PD must face. Uncertainty is experienced through changes in the body, in sufferer's ability to meet the day to day demands of life and therefore in their ability to sustain an individual sense of self (Habermann 1996; 1999; Stanley-Hermanns & Engbretson 2010). Dealing with a continual experience of uncertainty in everyday life and its consequences for the self therefore becomes a central problem facing many people with PD.

A key challenge therefore becomes trying to reconstitute the self in PD, to come to terms with the disruptions that occur in PD and to find a way to continue living a meaningful life. In a key theme within the phenomenological study of PD, Pinder (1992), Habermann (1999), Bramley & Eatough (2005) and Stanley-Hermanns & Engbretson (2010) all discuss how PD sufferers try to maintain continuity with their past lives and coherence with their past selves. In these studies PD sufferers tried to incorporate the changes that PD brought to their lives, but also tried to show that they remained the same person; 'I'm still me'. Sufferers use a variety of resources in order to reconstitute the self, including seeking information, advice and support about PD or focusing on the benefits of medicine and medications (Phillips 2006). This tension in the experience of the self, between reconstructing the self, incorporating PD into their lives while maintaining continuity with a past, biographical self becomes a central issue within research into PD's subjective experience.

A further important dimension of this body of work has been PD's changing experience as sufferers move through the illness. Many of the above studies have not specifically concerned themselves with how PD's experience changes over time. But a few have questioned its changing experience, paying particular attention to two periods of the disease; diagnosis and early illness (e.g. Phillips 2006) and later PD (e.g. Sunvisson

2006; Haahr *et al* 2010; 2011). Phillips (2006) describes the diagnosis of PD as 'dropping the bomb'; in which PD's diagnosis is a life changing event, fundamentally challenging a biographical sense of self and its future horizons. But by 'becoming informed' and 'negotiating with Mr Parkinson' sufferers could constitute a new sense of self over time, seeking information which could be used to come to terms with their diagnosis (Phillips 2006). Through such experiences sufferers could incorporate PD into their lives but could also reassert their own sense of self, continuing to exert agency over their worlds.

Attention has also been paid to severe PD, revealing how new concerns, experiences and needs come to the fore as PD progresses, challenging any self that had previously come to terms with PD. For Sunvisson (2006) and Haahr *et al* (2010; 2011) later PD continues to change the abilities of the physical body and therefore its relationship to an embodied self. As PD worsens eventually uncertainty and unpredictability become a new norm for everyday experience, continuing to bring changes to all the elements of life (Sunvisson 2006; Haahr *et al* 2011). Haahr *et al* (2010; 2011), alongside Montel & Bungener (2008) and Soulas *et al* (2011) examine the experience of PD after Deep Brain Stimulation (DBS); a neurosurgical procedure used to treat severe PD. Those undertaking DBS have lived with PD for many years, but once again find themselves experiencing a rapidly changing bodily state; a disruption experienced as a 'miracle' as their abilities suddenly return. However sufferers universally found their symptoms once again worsening, and had to reconcile themselves to a body once again slipping from their control. For Haahr *et al* (2010; 2011) and Sunvisson (2006) later PD is therefore the culmination of a series of disruptive experiences; a progression taking place over many years in which PD increasingly came to dominate every aspect of sufferers lives.

By examining this cross sectional work we can gain a sense of how PD's experience changes over time. How people experience the changes of PD, whether these are stages of the illness as measured by clinical instruments (e.g. the Hoehn & Yahr (1967) rating scale), or simple early, moderate/middle and later PD has seen little consideration. In early PD sufferers may face what Bury (1982) famously called biographical disruption before learning how to live with PD; how to reconstitute the self in their individual case (Phillips 2006). But this isn't a simple, one off process. As the illness worsens new problems arise and new symptoms come to the fore. Treatments will work, then fail, then work again as doses are increased, before again failing (Haahr *et al* 2010). Eventually PD threatens to overtake men's attempts to reconstitute the self, instead growing to dominate the lifeworld; trapped within a body which 'sets the agenda' (Haahr *et al* 2011). PD's subjective experience is therefore characterised by uncertainty, experienced within the body and its place in the world, and through the shifting experience of time both day to day and over the lifecourse.

In summary, So far, qualitative studies of PD's subjective experience have been under-represented within the wider literature in PD (Bramley & Eatough 2005; Stanley-Hermanns & Engbretson 2010). However the small range of studies turning a phenomenological lens to PD has revealed much about its subjective experience. Far from medical accounts of PD as a neurological disorder, PD comes to affect the unity of the body, self and world (Merleau Ponty 1962). Through the growing experience of uncertainty in the body's sensations and abilities, PD brings fundamental challenges to sufferers embodiment; their sense of their own bodies. As sufferers' awareness of the body changes in PD, so does its wider position within the world; how the body exists in relation to the objects and projects making up the world (Haahr *et al* 2010). And PD's experience is never stable; it is constantly changing. PD gradually gets worse, with

further consequences for sufferers lived experience. This changing experience continually challenges the self as PD's symptoms get worse. The primary goal of the work in this section has been to consider PD's individual, lived experience and its implications for PD care. However this work also points towards further gaps in our knowledge of PD, namely how PD's individual lived experience is also situated within the wider social structures and practices that define our everyday activities within the world I now consider a subset of the qualitative studies of PD and how they have drawn upon sociological and anthropological perspectives to further elucidate PD's subjective experience.

Sociological perspectives within current research in PD.

A rich tradition exists within the social sciences concerned with chronic illness and its experience. Chronic illness is interesting because it challenges many of the predominant attitudes of medicine; that illness is transitory, an abnormal life stage and something that can be 'cured' (Frank 1995). Its experience also reveals much about our normative experience of everyday life. In chronic illness sufferers can no longer meet these ideals, and must therefore attempt to come to terms with their new circumstances, showing the structures determining everyday life up for our inquiry (Bury 1991). And in a final area, chronic illness reveal how illness states are shaped by powerful social practices, famous examples being Parson's 'sick role' (Parsons 1951) or Goffman's approach to 'stigma' (Goffman 1963). But despite having much to contribute, so far these approaches have rarely been applied to PD (Dyck 1995; Chapple & Ziebland 2002; Solimeo 2008). However I argue that approaches widely adopted in the study of chronic illness could make significant contributions to our knowledge of PD. In particular, they give us a means to understand how PD's lived experience existed within a variety of social practices including gender and age. A

small number of studies located within medical sociology and anthropology have applied their perspectives to examine how PD is placed within the wider structures of society. I now turn my attention to these studies and how these perspectives can further improve our knowledge of PD.

First I examine how sociological work has been used to examine PD's social experience. Embarrassment and shame has been frequently highlighted as a key concern among PD sufferers (Caap-Ahlgren *et al* 2002; Schrag *et al* 2003). But by applying social constructionist perspective to the issue of stigma, Nijhof (1995; 1996) shows how and why PD sufferers experience embarrassment and shame in PD. Nijhof (1995) argues that shame occurs in PD through a very specific social process. First, PD's symptoms appear to break a number of powerful, socially sensitive 'rules' determining appropriate forms of public behaviour. Second, a number of PD's symptoms are embarrassing, but many are no, meaning something wider is going on here. For Nijhof, those symptoms that do induce shame do so because they 'break' socially sensitive rules about bodily competence, for example around the maintenance of its boundaries or around how bodies should act. Finally, through breaking these specific rules, the body and therefore the self, come to be labelled as deviant. We can see this in the physical display of PD's symptoms. Tremor, drooling and the stumbling, shuffling gait characteristic of PD could easily be misinterpreted as drunkenness. Alternatively incontinence and wider loss of bodily functions challenged competence by exposing sufferers to stigmatizing judgements around the loss of bodily control; of having a 'leaky' and therefore 'dirty', shameful body (Shildrick 1997). Sufferers could deal with these symptoms in different ways, but all had to respond to the public display of their bodies. Nijhof's work shows how interpreting PD using the sociological concept of

stigma gives us a means to understand a key element of PD's experience, locating it within wider social practices which subject bodies to social control.

A second study by Solimeo (2008; 2009) illustrates how PD's experience is shaped by wider social relations and inequalities. A gero-anthropologist interested in the anthropology of ageing, Solimeo uses ethnography to examine the cultural worlds of PD sufferers in the rural United States. For Solimeo when PD sufferers talk about PD they 'uniquely perform age and gender based on their social locations and chronological age' (Solimeo 2008 pS42). Thus, PD's subjective experience is inseparable from its position within these two social relations. First, Solimeo (2008) demonstrates how PD's experience is influenced by gender. As noted earlier, when quality of life is examined using gender; the social practices and relations determined by our biological sex, men and women had very different experiences. Here we see the different, gendered dimensions of these experiences. Women's accounts of PD focused their ability to maintain stereotypically female fields of competence including domestic activities and social relationships. Men on the other hand were concerned with the public display and performance of the physical body, with poor posture, loss of strength and difficulties with physical activities all challenging masculine ideals (Calasanti 2010). Both men and women therefore drew on their ability to 'perform' gender within their everyday acts in order to understand their PD. How PD's symptoms challenge gendered abilities and gendered ideals therefore have consequences for how sufferers make sense of PD.

Solimeo's work also shows how PD's experience is also influenced by social expectations around ageing and old age (Solimeo 2009). For many PD is interpreted through stereotypical assumptions of ageing; predominantly as a period of decline (Higgs & Rees Jones 2009). But these assumptions have to be re-considered in the face

of PD's effects, in which 'older age is no longer envisioned as a possible decline, but as an inevitable one' (Solimeo 2009 p18). Solimeo (2009) describes PD as being mediated through ageing, of being obscured by ageing and finally of accelerating ageing. PD mediates ageing in changing how ageing is understood; PD's meanings become inseparable from sufferer's judgements about age. PD also obscures ageing as sufferer begin to question what is PD and what is 'normal' old age. Finally PD accelerates ageing; sufferers seem to age faster and/or earlier than they should (See also Singer 1974). Solimeo's work on ageing and gender in PD is the only recent study explicitly engaging with these issues, but shows how PD, as part of wider social life is always situated within wider social structures and relations.

Summary

The overwhelming majority of research into PD has been biomedical and clinical in nature. However a small corpus of work within the health and social sciences has raised questions about PD's subjective, lived experience. When examined from these perspectives PD is shown up as a condition which leaves little of a sufferer's life untouched. From their relationship with their body, to their sense of time and space, and their willingness to interact with others, PD transforms all elements of an individual's existence (Haahr *et al* 2010). Many of these effects are not adequately considered, or even recognised within PD's routine treatment. In order to help sufferers to deal with all the challenges brought about by PD, it is crucial that care services gain insights into these experiences and their consequences. Further, as PD's treatment advances, so these lived experiences also change – from the biographic disruption occurring at diagnosis to the fundamental challenges faced in later PD (Phillips 2006; Haahr *et al* 2010; 2011). Therefore, while clinical and neurological models of research will rightly receive greatest attention in PD, a concern for PD's

subjective experience should be integrated more fully as part of a wider, unified medical and psychosocial; a bio-psycho-social approach to PD (Calasanti & Slevin 2006; Sunvisson *et al* 2009).

PD's individual experience also exists in relation to wider social structures and practices. So far, the research seeking to investigate PD in terms of the wider social structures or practices permeating social life is extremely limited. The two examples described above illustrate the potential improvements to our knowledge and care for PD that can be gained by using these social approaches to examine PD. In this thesis I concentrate on men's experiences of PD, a group who make up the majority of PD sufferers but who so far have seen little attention as a group with their own experiences and needs. Given the focus of this project, I now show how by engaging with the literature on critical and social gerontology and the study of gender and men's health we can gain further insights into PD's subjective, lived experience.

Part 3. How do gender and ageing contribute to PD's subjective experience?

In the third section of this review I discuss the roles that perspectives adopted within social gerontology and men's health can play in informing our knowledge of PD. The work of Solimeo (2008; 2009) shows the utility of paying attention to the roles gender and ageing play in PD. As more men are living into deep old age, the importance of this topic has led Van Den Hoonaard (2007) to describe ageing and masculinity as 'a topic who's time has come' (p227). Although still a marginal area of inquiry, questions of gender and its interplay with ageing beginning to see growing attention (Arber *et al* 2003; Calasanti & Slevin 2006; Calasanti 2010). Recent scholarship within gerontology has argued that ageing and gender can best be understood as intersecting processes (Arber *et al* 2003; Calasanti 2004; 2010; Krekula 2007). In this section I therefore

consider how these two bodies of literature; critical and social gerontology and critical men's health can contribute to a socially situated knowledge of PD. In doing so, we can study PD in a way which acknowledges the complexities of ageing and the lifecourse and gender, gender inequalities and gender relations and the roles they can play in PD care.

Social gerontology, ageing and chronic illness

The study of ageing has largely fallen within the remit of Social Gerontology, a sub-discipline within gerontology which questions the place and status of older people in society and the interplay between wider social structures and the production of older age (Higgs & Rees Jones 2009; Innes 2012). Kontos (2005) describes gerontology as a 'border crossing' traversing medicine, health and social science, constituted through multi-disciplinary scholarship. Recent 'critical' forms of social gerontology have sought to challenge problematise ageing and age relations by arguing that much of the 'problems' of older age are socially constructed, for example by examining the various social inequalities occurring in old age or how ageist stereotypes are perpetuated within society (Bytheway 1995; Minkler & Estes 1999; Calasanti & King 2005; Powell 2006; Jones & Higgs 2010). As part of this tradition, critical forms of gerontology have illustrated how ageing is situated within powerful political and medical discourses, each defining what we know as older age and each with consequences for older people's lives (Powell 2006; 2009; McDaniel 2009; Pickard 2009a; 2009b; Higgs & Rees Jones 2009).

I focus on the growing approach to embodiment within gerontology, an approach which has problematised predominant social discourses of ageing, for example as a period of illness and which have relevance to the study of PD. Although widely adopted

throughout the social sciences the paradigm of embodiment has only comparatively recently begun to make inroads within gerontology (Laz 2003). Over the last decade gerontologists have begun to engage with the sociological paradigm of embodiment and the lived body (Laz 2003; Clarke & Griffin 2008). Embodiment has proved particularly influential in the study of chronic illness, where it has contributed to a shift away from dualistic thinking in which the body is thought of as either a physical, biological object falling under the remit of biomedicine or alternatively a social, discursive construction formed through social practices (Benner 1994; Toombs 2002; Sunvisson 2009). Such perspectives can also be usefully applied to ageing bodies, where embodied perspectives have been used to examine how old age comes to be known through both the physiologically ageing body and the space these bodies occupy in society (Shilling 2003; Laz 2003). Embodied perspectives within gerontology conceptualise the body as simultaneously being material, biological entities and social practices (Turner 1992; Twigg 2004; Calasanti 2005; Robertson 2006b; Williams 2006):

> *Within gerontology (perspectives on the ageing body) translate into two contrasting views. The first gives primacy to the biological bases of ageing; the second emphasizes old age as a socio-cultural phenomenon (...) Recent scholarship (in gerontology) works to overcome the dualities suggested by these segregated strains of scholarship by emphasising bodies as simultaneously material **and** constructed (original emphasis). That is, bodies have both a physical flesh and blood reality as well as an experiential dimension that is subject to interpretation (Calasanti 2005 p9).*

As Calasanti (2005) notes, physical changes do occur in old age, but these on their own do not explain ageism, income inequalities between the genders in older age, or a lessened likelihood for older people to receive a variety of forms of medical treatment. 'Rather it is the meaning we give to these changes that matters' (Calasanti 2005 p10). An embodied approach to ageing therefore problematises simple constructions of

ageing for example as either a period of illness and decline or as an active, successful form of ageing, and the biological and discursive bases through which these constructions emerge (Williams & Bendelow 1998; Wilde 2003; Pickard 2010).

An embodied approach to ageing has proved particularly useful in understanding how illnesses associated with ageing; Arthritis, Prostate Cancer, Stroke, Alzheimer's Disease and the dementias and of course PD are intertwined with the experience of ageing and ageing bodies (Toombs 2002; Phinney & Chesla 2003; Higgs & Rees Jones 2009). For example Sanders *et al* (2002) demonstrates how experiences of osteoarthritis are judged in relation to older age. Although highly disruptive in their effects on everyday life, symptoms of osteoarthritis can also be normalised, thought of as a natural consequence of growing old. Ageing provides a means of explaining the presence of osteoarthritis, and therefore of coming to terms with its disruptive effects. Faircloth *et al* (2004a; 2004b) also reinforce this issue with their exploration of how older stroke sufferers use social expectations of ageing when making judgements about its lived experience. In a departure from accounts of chronic illness as 'biographical disruption' (Bury 1982), Faircloth *et al* (2004a; 2004b) describe stroke as a form of 'biographical flow', in which sufferers draw on meanings and expectations related to ageing in order to make sense of stroke and its effects. Rather than viewing stroke as a catastrophic event, it is instead approached as a 'normal' crisis; a further (albeit negative) event within an individual's life story. Through the examples of Sanders *et al* (2002) and Faircloth *et al* (2004a; 2004b) we can see how the experience of chronic illness is intertwined with meanings of ageing; both the biological realities of ageing bodies and also how ageing is used as a resource to make meaning in illness (Calasanti 2005; 2010).

The existing work on illness in old age suggests that older people with PD are also likely to use expectations of ageing when making judgements about PD (Solimeo 2009). Although much of the literature investigating PD's lived experience has examined PD's effects on the body, relatively few of these studies have considered PD within the wider social contexts in which ageing bodies are 'produced' (Powell 2006; 2009). But we can also question how people with PD interact with these various discourses and practices, including medical practices within their everyday lives and within their own ways of understanding both ageing and its interplay with illness (Mattingly *et al* 2011; Twigg *et al* 2011). Older men with PD will understand their illness through predominant ideals around gender and ageing, but can resist and remake these practices to their own ends, reflecting their own living situations and their own needs. Medicine may well provide discourses determining how PD and the body in PD should be known. But older people with PD will use these to draw meaning from their experiences according to their own lived reality. Ageing is a physiological experience, but is also a social structure, which individuals use to understand and interpret their own lived realities.

Masculinity and illness

I now review the literature on the contribution masculinity makes to the experience of health and illness. Based on the idea that men occupy a prioritised, patriarchal position in social life, feminism has a long history of problematising gender relations (Bowlby 1997; Calasanti 2004). But in addition to marginalising women masculinity and its various structures also possess the power to subordinate different groups of men (Connell 1995; Robertson 2007). Any prioritised account of masculinity will differentially shape the lives of individual groups of men, with many groups of men occupying marginalised positions in relation to dominant masculine norms (Connell

1995; Connell & Messerschmidt 2005). The burgeoning literature on men's health has led to important advances in our knowledge of the relationship between gender, health and illness. But these studies have almost universally focused on youth and middle age; accounts of the relevance of masculinity to the lives of older men have been remarkably absent (Meadows & Davidson 2006; Thompson 2006; 2008). Questions can therefore be raised about the importance of masculinity in older men's lives (Thompson 1994; 2008; Fleming 1999; Calasanti & Slevin 2006).

In order to consider the role masculinity plays in illness in old age we must first discuss how masculinities have been considered within social theory. Perhaps the most influential approach within critical men's health has been Connell's concept of Hegemonic Masculinity (Connell 1995; Connell & Messerschmidt 2005; Robertson 2007; Bennett 2007). Hegemonic masculinity is the dominant model of male social identity, prioritising men's position within a given culture (Entwistle 2006). The characteristics defining hegemonic masculinity can vary, but within contemporary western culture its ideals include physical strength, being able bodied, possessing high economic and social status and being white, middle class, and heterosexual (Courtenay 2000). And arguably, in a shift from historical norms of western modernity, hegemonic masculinity is becoming increasingly accessible only to those in youth (Fleming 1999; Meadows and Davidson 2006). Hegemonic masculinity does not simply represent the largest group of men; indeed relatively few men can meet its ideals. Rather it is where institutional power is concentrated, shaping other forms of masculinity and therefore influencing the lives of all men. As a result it is open to change; a relational process which is also influenced by other social practices (Connell 1995).

Hegemonic masculinity has proved particularly influential in the growing study of masculinity, health and illness (Robertson 2007; Smith & Sparkes 2008; Carless &

Douglas 2008). Men's health is almost universally poorer when compared to women, while men's health behaviours, including their reduced willingness to seek help from health professionals, their higher likelihood of suicide, and their possessing smaller, less emotionally supportive social networks are all damaging to health (Robertson 2007; Emslie & Hunt 2009; Johnson *et al* 2011; Oliffe *et al* 2011). Masculinity shapes the experience of individual illnesses including prostate cancer; an illness limited to men (Moynihan 2002; Chapple & Ziebland 2002; Kelly 2009); heart disease; an illness stereotypical of men (Emslie & Hunt 2009; Robertson *et al* 2010), and depression and breast cancer; illnesses existing in opposition to men (Danielsson & Johansson 2005; Emslie *et al* 2006: Donovan & Flynn 2007). Masculinity has also been linked to men's wider health behaviours, such as exercise, sports and sporting injuries, which can be both beneficial but also potentially destructive to health (Chapple & Ziebland 2002; Smith & Sparkes 2005; Tulle 2008; Wiersma & Chesser 2011). These studies all show how masculinity and male gender relations are implicated across a variety of illness states, giving insights into how PD's experience may also be gendered.

More interestingly much of the above work has also examined how masculinity provides men with a resource through which they can make sense of illness. Men may engage with hegemonic norms of masculinity but be left feeling marginalised as they can no longer meet its ideals. But masculinity is not simply a negative characteristic destructive to health. Men can also remake their own sense of masculinity in order to successfully negotiate illness. Through men's talk of illness, masculinity can either be reinforced, re-appropriated or even resisted depending on men's experiences and the stories they tell of them, promoting well-being if men can successfully show that they remain men (Emslie *et al* 2006). Illness and its effects may also lead men to reject hegemonic norms, instead seeking alternative ways of asserting their masculine status.

Chapple & Ziebland (2002) discuss how men with prostate cancer face a loss in gender status due both to their symptoms and the consequences of treatment. Donovan & Flynn (2007) describe similar findings in the case of male breast cancer but also consider how men reconstruct their seeking help from medicine, speaking of their actions in such a way as to reassert their masculinity. Emslie & Hunt (2006) discuss how men with depression could find themselves pressurised by masculinity but could also find ways to draw meaning from their depression which either resists or reinforces hegemonic meanings. By showing that they had become more 'attuned' with their emotions they could therefore claim that depression had made them 'better men' (Emslie & Hunt 2006). In sum, masculinity provides men with an overall ideal against which their own experiences can be judged, but also gives men a resource used to reinforce men's presence in the world as men.

Masculinity, ageing and illness; intersecting processes?

Although masculinity has become a key concept in gender studies it has only recently begun to gain traction as a means to study older men (Thompson 2006; 2008; Calasanti 2010). Gerontology has not yet adequately considered how older age is gendered, while gender studies have largely ignored how masculinity is experienced in old age (Arber *et al* 2003; Calasanti & King 2005; Blundo & Bowen 2008). It has been left to a relatively small number of feminist gerontologists to adapt masculine theories and models to old age (e.g. Arber *et al* 2003; Calasanti 2004; Calasanti & Slevin 2006). Yet this work is at a small scale and early stage, as seen in Spector-Mersel's (2006) argument that gerontological conceptualisations of what makes up an age appropriate masculinity have not yet reached critical mass, meaning there remains much to do in developing wider theories of masculinity in older age (Thompson 2008).

A key question in gerontological studies of gender has been how ageing and gender interact with each other to form new forms of social relations and social inequalities. Twigg (2004), Krekula (2007) and Calasanti & Slevin (2006) argue that an intersectional approach is the best means of understanding ageing and gender (Giddings *et al* 2007). From an intersectional perspective multiple sources of inequality such as gender, age, class or ethnicity are not layered structures; what Krekula (2007) describes as 'multiple jeopardy'. Instead together gender and ageing create wholly new, forms of social relations (Calasanti 2004; Calasanti & Slevin 2006). Older women's and older men's lives are not the same because they are old but different because of their gender. Rather ageing and gender together lead to differing experiences for older men and older women or for men in middle and older age. Therefore in order to understand the complexities of both gender *and* ageing we must consider them as intersecting processes (Calasanti 2005).

An intersecting perspective has been used to examine an ageing masculinity in relation to illness (Rozario & Derienzis 2009). Activities that maintain masculine privilege throughout the lifecourse; sports, and various risk taking behaviours can lead to poorer health in older age (Calasanti 2005; Thompson 2008). Tulle (2008) and Wiersma & Chesser (2011) also argue that maintaining athletic and sporting competencies remain central in reinforcing masculine status in older age. Through accounts of sporting ability men continue to portray themselves as strong and vibrant men; the benefits to health and also to masculine status are therefore worth the risks that these acts may entail. This remains true even in older age, but does take into account men's changing physical abilities; older men still expect and try to be physically active, but define their physical abilities in age appropriate forms; e.g. playing golf instead of football, or bowls instead of golf. Seale & Charteris Black (2008) discuss how younger and older men with

cancer differentially use masculinity to negotiate their contact with medicine. Older men suffering from cancer seek information not only to find out about their condition, but also to build a position for themselves as lay 'experts' in relation to medicine. In addition, older men appeared more confident than younger men within their clinical encounters, being far more likely to question medical knowledge (Seale & Charteris Black 2008). Information seeking reinforces medicine's legitimacy, but is also used by individual men to negotiate and where necessary resist clinical power in their day to day lives.

A key issue in studies of masculinity, health and illness is how men express and 'feel' their emotions in relation to health and illness. The stereotypical view of men as naturally unemotional and rational has been fundamentally challenged within much of the work on masculinity and health (Courtenay 2000; Robertson 2006a, 2007). At first glance many accounts of men's emotional expression have focused on doing rather than feeling, with men being action rather than communication orientated, that men 'don't talk about their feelings', or that talking about 'doing' is a way to avoid talking about 'feeling' (see Moore *et al* 2006 for an example in PD). However, recent studies of men's emotional expression suggest that the split between feeling and doing is a false dichotomy. For men, doing is not simply a means for men to express emotion, but rather is emotion (Bennett 2007; Robertson 2007). Rather than activities acting as a means for men to talk about their feelings, they are the ground through which men's emotions take place and are played out. When talk about their acts, they simultaneously do emotion. Such a position has been used to understand several elements of older men's experience. For example, Bennett (2007) discusses widowhood and how older men negotiate the often complex emotions accompanying this experience. Men seek to construct meanings of widowhood for themselves based

upon acts expressing masculine ideals, dissociating themselves from an overtly emotional experience. For example, after undergoing an appropriate period of mourning, men prefer to present themselves as single rather than widowed. Doing so enables men to engage with more desirable forms of masculine identity, to keep any overt displays of emotional expression in check, and to negotiate the deeply emotional experience of widowhood in male appropriate forms. Ribiero *et al* (2007) and Twigg (2000) pay attention to how older male carers experience emotional connections within the act of caregiving. Men talk of care giving and care receiving as a functional and productive rather than emotional activity. When talking about their care giving acts, men reconstruct care as a male activity, avoiding feminine associations with care and giving them responsibility and authority over those they care for or those that care for them. Through their various experiences; of illness, of widowhood, of care or of sport, older men continue to engage with hegemonic ideals of masculinity, but do so in often dynamic and age appropriate ways (Spector-Mersel 2006).

By using ageing and gender as intersecting processes, we can come to understand PD as an illness which profoundly challenges many masculine gender norms (Solimeo 2008). Physical strength, functional independence, and emotional control are all key aspects of being a successful man, and are all likely to be threatened by PD (Connell 1995; Bennett 2007; Solimeo 2008). But masculinity also gives men a means to negotiate PD's effects in their lives. Masculinity becomes a resource through which men can negotiate medical authority, the growing experience of care, or their changing lived bodies, doing so to reassert positive meanings, or conversely finding themselves lacking according to these ideals (Thompson 2006; Bennett 2007; Seale & Charteris Black 2008). In examining men's lived experience of PD, it is therefore appropriate if

not essential for us to question how its experience occurs in relation to both masculine gender relations and their expectations of ageing and older age.

Summary

To understand how PD is experienced as part of wider social life we must go beyond just examining PD's subjective experience. Although they have not collaborated as closely as they might, and although they have rarely been applied to PD the sociological, anthropological and gerontological literature on health, illness and gender tells us much about the complexities of chronic illness. This knowledge can usefully be applied to the study of PD. Whether it is considering how PD is understood as a potentially stigmatizing condition, how PD leads to profound changes in sufferer's embodiment, or how ageing and gender are implicated in its experience, these forms of knowledge can make significant contributions to our knowledge of PD and its subjective experience.

Through this work we can consider PD in terms of an ageing embodiment; the changes occurring within the body as a result of both illness *and* ageing (Solimeo 2009). For men with PD their relationship with their bodies changes fundamentally, with these changes forming a key focus of this thesis. But how PD comes to be known as a problem in men's lives is as much due to social and discursive practices as it is due to biological disorder (Calasanti 2005). The medical account of PD as a neurological disorder has powerful consequences for how we know and treat PD. But this production is also positioned within wider practices shaping how ageing and ageing bodies are known and how individual's respond to their changes. These discourses, although often hidden to everyday experience have direct impacts on older people's daily lives. It is through these changes, to men's everyday lives and to their everyday

activities that we can explore the intersections between ageing, gender and PD. Through taking such a perspective we can therefore access both PD's effects, and situate them within the various resources men use when interpreting and making meaning from their illness.

Conclusion

In this review I have discussed the bodies of literature relevant to the study of men's experiences of living with PD. Research into PD has been dominated by basic and clinical research. Although bringing major benefits to sufferer's lives the focus on clinical research has inadvertently led to a relative neglect of questions relating to PD's individual, subjective experience (Solimeo 2008). We can learn lessons from the study of a range of chronic illnesses to inform our knowledge of PD (Dyck 1995; Phinney & Chesla 2003; Stanley-Hermanns & Engbretson 2010; Innes 2012). Perspectives concerned with both PD's lived experience and its relation to wider social practices are not a nice addendum to clinical research, interesting but of little practical benefit. Instead these perspectives form an essential part of our knowledge of PD, informing us of sufferer's social backgrounds and lived realities in which PD's routine treatment takes place. The current gaps between the treatment of PD's motor and non-motor symptoms, the current failure of PD services to adequately treat those problems most distressing to patients, and the difference between patient and clinical judgements about symptoms can at least in part be attributed to a neglect of studies of PD's lived experience. Therefore, building our knowledge of PD's wider effects is crucial if we seek to improve the lives of those suffering from the disease, both now and in the future.

It is also important to recognise however that sufferer's experiences of PD do not simply result from pathological, physiological change; they are mediated by social practices. Such practices include sufferers position within the world according to their gender, along with their expectations of ageing and old age. Given PD's character as an illness predominantly affecting older men, the issues of gender and ageing are therefore key concerns to any sociologically informed study of PD. These issues therefore form the key focus of this thesis. By listening to men's stories of PD, we can see the issues of importance to their lives, pointing towards the provision of truly person centred care (Kleinman 1988; Solimeo 2009).

Chapter 3. Methodology and methods

Introduction

The previous chapter sets the scene for my wider thesis. In PD there is a clear gap between the provision of PD services and sufferers wider needs. We can better respond to patient's needs by paying greater attention to PD's lived experience; how PD affects the minutiae of sufferers lives and what they do about it. In addition we can examine how this experience is situated within the wider social world, and therefore how it is influenced by the various social practices which constitute the world, including ageing and gender. In this chapter I describe the methodological approach and research methods I use to access men's lived experiences. To do this I use a phenomenological methodology concerned with men's embodied experience of the lifeworld, combined with narrative research methods interested in the stories men told about their suffering (Kleinman 1988). Through the use of this methodology and methods I hope to provide insights into PD's lived experience; the everyday problems men with PD face, what they do about them and in sum, how they draw meaning from a changing lifeworld with PD.

Aims & Objectives

The overall aim of this thesis is to gain insights into the following question:

What is it like for men to suffer from PD; what is PD's 'lived experience'?

I also explore the following four questions, each forming a separate objective for this thesis;

1. ***What are the problems men with PD face? What stories do men tell of these problems, and how do men understand PD through these stories?***
2. ***How do men respond to the various problems PD brings to their lives?***
3. ***What role does gender and ageing play in PD's lived experience?***
4. ***What implications do these men's experiences have for service delivery and clinical practice?***

This chapter is divided into three sections. In part one I describe my research methodology. I investigate PD's effects on the phenomenological lifeworld, focusing on PD's effects on the lived body. Men communicate their experiences of PD through narrative; by telling stories about their PD. By looking at these stories through their content and how they are told, valuable insights about how men understand their illness and respond to its various effects can be gained. Furthermore, by examining how these narratives are 'emplotted' I hope to explore how ageing and gender together contribute to PD's lived experience. In part two I account for my research methods, combining narrative interviewing with a photo elicitation exercise (Mishler 1986; Oliffe & Bottorff 2007). I then discuss the sample design, consent procedure, inclusion and exclusion criteria and approach to data analysis. Finally I conclude in part three by discussing the various ethical and reflexive dilemmas arising during this work.

Part 1. Research Methodology; The embodied experience of the lifeworld in PD

Phenomenology and the lifeworld

The central standpoint I take in this thesis is phenomenology. Phenomenology has a long tradition as philosophy and methodology across both the health and social sciences (Merleau Ponty 1962; Schutz 1967; 1971a; Benner 1994; Toombs 2002; Sunvisson *et al* 2009; Carel 2011). Although there are many different types of phenomenology, what characterises a phenomenological approach is a concern towards phenomena as they present to consciousness rather than how they are interpreted; 'to the things themselves' (Toombs 2002; Dowling *et al* 2007). Originally conceived by Husserl, phenomenology has since developed in numerous directions, including Heidegger's (1962) concern for the question of being; Sartre's existential phenomenology (Sveneaus 2009); Merleau Ponty's (1962) concern for embodiment; the phenomenological methodology of Schutz (1967) and the application of phenomenology to medicine by Benner (1994) and Toombs (1988, 2002). Drawing on this work phenomenology has grown throughout the health sciences and social sciences interested in health, where it provides a means to theorise and conduct empirical research into the subjective experience of illness (Schutz 1967; Seamon 1980; Dowling 2007). Phenomenology therefore provides the methodological foundation to this thesis.

I draw on two issues pertinent to the phenomenological study of PD; the lifeworld and its experience through the lived body (Merleau Ponty 1962; Van Manen 1990; Toombs 2002). The lifeworld is the everyday world; the mundane, taken-for-granted background of our lives and the arena in which our everyday experiences become meaningful (Husserl 1970; Leonard 1994; Dyck 1995; Van Manen 1990; Benner 2000;

Dowling 2007). The lifeworld is the world of experience; the world as it appears to our perceptions. It is the world before we think about it or before we interpret it, for example through the physical, natural or social sciences (Husserl 1970; Pickles 1985; Heelan 2002). Accompanying wider critiques of qualitative inquiry from outside the interpretive sciences, a common critique of phenomenological perspectives is that they are simply concerned with individual experience. Yet although we each develop our own meanings based on our individual presence within the lifeworld, the lifeworld is not an individual phenomenon, closed to collective understandings. Rather our lifeworlds are intersubjective; our meanings are shared with others, shaping how we know what we mean and how our meanings are shared with others within a given culture (Leonard 1994; Benner 2000; Crossley 2001). Through this, intersubjectivity gives us a means to understand the lifeworld as it is inhabited by others, making studies of the lifeworld a worthwhile form of inquiry.

In our everyday experience the lifeworld is usually invisible to us. We are always-already present in the lifeworld, permanently in a state of what Heidegger called *'dasein'* or 'being there' (Heidegger 1962; Sveneaus 2011). Yet we do not routinely see or think about the lifeworld in our everyday projects (Heidegger 1962; Schutz 1967). It is only through a deep reflection upon our daily lives that we can access the lifeworld and the elements constituting its experience (Van Manen 1990). Illness is however one arena of human experience which forces us to reflect upon the lifeworld (Leder 1990; Toombs 2002). Illness brings the structure of the lifeworld into relief in numerous ways. In illness, suddenly we no longer seem to 'fit' in the world. We may no longer be able to fulfil our normal activities, meaning many of our taken for granted approaches to life suddenly have to change (Toombs 2002). As described by Scarry (1985), by Kleinman (1988) and by Good (1994), the various experiences of illness;

pain, fatigue or dysfunction all have the potential to 'unmake' the lifeworld (Bullington 2009). By attending to lived experience within the lifeworld, phenomenology therefore gives us a means to investigate how the onset of illness, including PD affects the everyday lives and everyday realities of sufferers.

The lifeworld and the lived body

I now expand on this concept of the lifeworld by describing its constituent elements. Merleau Ponty (1962) in a phenomenological approach later expanded by Van Manen (1990) conceived of four 'existentials' through which we experience the lifeworld; lived body, lived time, lived space and lived relationality. Living with PD will affect all of these elements of the lifeworld, individually and in combination (Dowling 2007; Haahr *et al* 2010). In this thesis, I use these existentials as sensitising concepts; a 'starting point' for qualitative study by providing means of organising and accessing data through which analysis can take place (Charmaz 2003; Bowen 2006). The lifeworld existentials provide a beginning for my analysis, a means to organise my data and a way through which I can begin to consider the complexity of men's lived experience.

I briefly discuss each of these existentials in turn. Lived body refers to our body and its position in the lifeworld (Toombs 1988; Leder 1990). The lived body is not just our physical presence in the world. Rather lived body refers to our embodiment; how we experience the world through our bodies. Illness, including PD can change our everyday experience of the body, forcing the body to 'appear' to sufferers through its various motor and non-motor symptoms (Leder 1990; Haahr *et al* 2011). The second existential is lived time (Merleau Ponty 1962; Ricoeur 1980). Although we measure time chronologically as clock time, within the natural attitude we do not experience time in this way; as a chronological, linear succession of events. Rather we experience

lived time in a threefold manner, looking back to past biography while also looking towards an anticipated future, drawing on both in order to understand our present lives (Schutz 12971; Ricoeur 1980; Kierans 2005). Illness can transform this everyday sense of time; both in terms of its everyday flow and its three-fold experience. Lived space refers to our movements in the world and the emotions evoked through our everyday presence in space (Seamon 1979; Rowles 2000). In illness the body's ability to move through space changes, itself altering sufferers perceptions of the environment. Finally lived relationality describes our everyday encounters with others, for example how we understand the nuances of our everyday forms of communication. PD alters men's experience of both these existential elements; speech loses its volume and clarity, while sufferers now experience themselves through the gaze of others (Nijhof 1995; Tickle Degnen & Doyle Lyons 2004).

Men's experience of the lived body takes central place in my study of the lifeworld in PD. It is therefore worth exploring PD's embodied experience in more detail. Merleau Ponty coined the concept of lived body as; *'the body as it is immediately experienced in a non-reflective or pre-reflective manner'* (Toombs 1993 p 51). In a critique of the Cartesian mind-body dualism historically fundamental to biomedicine, we do not experience our bodies as a machine separate to the 'mind' or to the self (Toombs 1988; Sunvisson *et al* 2009). Rather we experience life through an embodied being-in-the-world in which the body, mind and self all exist in a unified 'field of presence' (Merleau Ponty 1962; Bullington 2009; Sveneaus 2011). The mind, the body, the self and the world are not separate entities; they are unified, each intertwined with the other. Anything that affects the body affects the world and vice versa. Yet in our day to day lives we do not have to attend to this experience. In his seminal work 'The Absent Body', Leder (1990) describes the body as an absent presence. Our bodies are

essential to our experience of the lifeworld, however this experience is dependent on the body's self-concealment; our bodies provide the embodied but unconscious medium for our habitual presence in the world (Leder 1990; Bullington 2009).

A number of experiences can force us to consider the body and its place within the world; for example the proprioceptive awareness of the body held by athletes in training (Tulle 2008). But for most of us it is most commonly illness that brings the lived body into relief (Toombs 1988; Leder 1990; Svenaeus 2009). In illness the body is brought the foreground of our conscious experience (Frank 1996; Thomas-MacLean 2004). When we are in pain our whole lifeworld collapses, instead we become focused on our pain and the body part in which pain is located; our attention turned inward rather than oriented towards the wider world (Scarry 1988; Bullington 2009). In illness the body is brought into awareness through its various disruptions; what Leder (1990) calls 'dys-appearance'.

Dys-appearance affects the body's position in the lifeworld (Kleinman 1988; Leder 1990; Good 1994). Consider a man who breaks his leg during a football match. The break, although located in the body also transforms the lifeworld. After the injury he can expect a period of pain and immobility, during which he may suddenly find himself needing to use a wheelchair or crutches. Such effects disrupt the body's ability to move around lived space. Spaces may no longer be accessible; for example he may suddenly find it difficult to climb stairs. And until the leg heals he will be unable to play football. Time is also remade; it may take weeks to heal, while even upon healing it will take several weeks or months to regain his fitness, to be able to play again. A social life, organised around the sport can be temporarily curtailed as the man can no longer take part. But with time and care the injury will heal, and once healed he can expect his limb to return to its normal functioning. Although prolonged dys-appearance in this

case is only temporary, the body returning to an absent state (Leder 1990; Toombs 2002). However in many cases dys-appearance can be more fundamental. In the same example the leg break may not heal cleanly, leaving the man with a limp or with frequent pain. He may need further operations to repair the break. In the worst case he may be unable to play football again. In such a case the physical body changes permanently, irrevocably changing the foundations of the lifeworld. Thus illness in its various forms can transform how we experience a changing lived body and how we make new sense of a shifting world.

How illness affects the lived body and therefore the lifeworld can therefore be used to investigate men's experience of PD. With the onset of PD all sufferers will face profound changes to the lived body (Pinder 1992; Bramley & Eatough 2005). Symptoms such as tremor are highly visible, both to the self and to other people. The need to take medications several times a day for the rest of men's lives will have transformative effects on men's sense of time. Space will also change as mobility difficulties affect their ability to simply move around. And both communication difficulties and the new found visibility of the body will reshape men's relationships with the family, friends and strangers in the wider world. All of these experiences will affect the unity of an embodied self for those with PD, and all have their origins within a changing lived body. We can therefore question the nature of this disruption in PD, its consequences for the lived body and its effects on the wider existential elements of the lifeworld. If we accept Leder's theorisation of illness as a form of dys-appearance we can ask a further question; how does the body in PD 'dys-appear' and what are their consequences for men's lifeworlds? To answer such a question we must also consider how men with PD talk about their illness, and through this talk make sense of

it to themselves and to others. This is where I turn my attention to the final element of my methodology; that of narrative.

Narrative and PD; telling stories about men's experience of PD

Stories are an everyday feature of life; we routinely communicate and understand our lives by telling stories about our experience (Kleinman 1988). Narrative has proved particularly influential in phenomenological studies of illness, where the telling of stories can be used to comprehend the changes illness brings to life, and how illness sufferers can find ways to reconstruct their worlds (Williams 1984; Hyden 1997). As discussed by Good (1994);

> *"Narrative, the imaginative linking of experiences and events into a meaningful story or plot is one of the primary reciprocal processes of both personal and social efforts to counter this (dissolution of the lifeworld) and to reconstitute the world"* (Good 1994 p118).

By paying attention to narrative, the stories illness sufferers tell, we can gain access to their lived experience; what they talk about, how they talk about them, and how meanings are shared with others (Kleinman 1988; Frank 2002). Through careful examination of the stories people tell about illness we can therefore gain a greater attunement to how suffering is endured and how meaning results from the socially situated nature of this suffering (Kleinman 1998; Docherty & McColl 2003).

There are a number of different approaches to narrative. Such approaches include biography and the continuance of the self or linguistic approaches concerned with how narratives are constructed through language (Bury 1982; Mishler 1986; Riessman 1993; Leiblich *et al* 1998). Narratives can be concerned with a reflexive self, how people

think about things and through these try to portray a rational self, distanced from their emotions; or an embodied self; told through what they do and what they feel (Williams & Bendelow 1998; Reeve *et al* 2010). Furthermore stories also serve differing purposes for the teller, using stories in different ways for different audiences. A story being told to a researcher is very different to one told to a family member, a friend or a doctor. When people tell stories they do so with a variety of objectives; to make sense of their experience of illness and reconstruct their lives; to explain their illness to others; to project their identity with a given social setting or to share their experiences with others in order to create a collective account of suffering (Hyden 1997). Indeed a single story may be told in order to meet any or all these objectives. Narratives are therefore socially situated; a medium for conveying shared cultural experiences, formed within the context of our everyday encounters (Hyden 1997).

At their most simple, narratives deal with two central elements; what people say and how they say it. First, illnesses sufferers use narrative as a means to account what happened to them, giving sufferers a means of recounting and therefore representing experience (Good 1994). Within narrative accounts of illness sufferers describe what happened to them, when and where it happened and what its consequences were. Through telling stories men can attempt to reconstruct their lives, trying to incorporate illness into a biographical identity (Williams 1984; Docherty & McColl 2003). Narrative gives men a platform to negotiate the experience of chronic illness; either by negotiating the biographical disruption occurring in illness and find ways to reconstruct the self, or to position illness within the wider narrative of a person's life story (Bury 1982; Williams 1984; Hyden 1997; Faircloth *et al* 2004a; Reeve *et al* 2010). A careful attunement to the stories people tell can show us how illness sufferers attempt to

make meaning and order from their changing experience of the world (Good 1994; Mattingly 1998; Rimmon-Kenan 2006; Randall 2010).

There is also a second core element to narrative; how stories are told and the resources used to tell them (Bruner 1990; Riessman 1993; Hyden 1997). Here narratives are concerned with emplotment; the range of resources used to assemble narratives in order to convey a particular point (Dell Vecchio-Good *et al* 1994; Mattingly 1998). We emplot our narratives; we select certain events and leave others out. Some points are exaggerated while others are marginalised or left out. We might also tell our stories out of their chronological sequence or change them according to our audience. We also use a variety of linguistic resources, using particular metaphors or turns of phrase to communicate experience (Riessman 1990). These terms and the processes of selection behind them are not value free; it is through them that we tell the particular story we wish to tell. Narratives are not an objective 'truth', a transparent account of events; they are always situated within our social context and personal prejudices (Hyden 1997). By considering how narratives are assembled and told, we can also gain insights into lived experience.

In this thesis I am concerned with both the basic elements of narrative described above. First I am interested in the content of men's narratives and what they tell us about PD's lived experience (Kleinman 1988). What problems do men talk about and how do these problems affect their lives? For example, how do men talk about the changing lived body or their changing experience of time? Both are likely to be transformed in PD, and both are likely to be told through stories (Ricoeur 1990). And importantly, what do they do about PD; how do they respond to PD in order to negotiate a changing self and a changing lifeworld (Polkinghorne 1996; Habermann 1999; Charmaz 2002)? But I am also concerned with how men told these stories. How

are men's stories emplotted, and what resources are used in their emplotment? What language do men use to talk about PD and how do they reflect their actions? And central to this study, how do men draw on expectations of gender and ageing when telling stories about their PD? By examining men's stories of PD, we can therefore examine how men with PD give voice to their suffering, the resources they use in doing so and how this suffering is found within the collective experience of the lifeworld (Kleinman 1988; Good 1994; Dyck 1995).

Summary

The goal of this thesis is to investigate men's experiences of living with PD. Men with PD face a series of challenges; not least a lived body 'dys-appearing' in its everyday experience (Leder 1990). As the body changes with PD, so do the other existential structures of the lifeworld; lived time, lived space and lived relationality. Many of these changes are made sense of through narrative; the stories men tell about their condition and its effects on their lives. By paying attention to what men talk about in their stories and how they talk about them, we can gain insights into PD's lived experience; how PD 'unmakes' the lifeworld and what men do to reconstitute this world (Good 1994). Men also used a range of wider resources when telling stories about their PD. I therefore also consider the role ageing and gender play in the stories men tell about PD. All the men spoke about ageing and gender in their stories; whether it was making judgements based on expectations of an age based decline or by sustaining a physically active self. In doing so they engage with gender relations in diverse ways, reinforcing, re-appropriating or resisting both age and gender norms (Meadows & Davidson 2008). By taking this approach, I therefore hope to bring about important insights into PD, its effects on men's lifeworlds and how health services can therefore help men to better negotiate these changes.

Part 2. Research methods.

I now describe my methods of data collection. My approach is qualitative and is organised around a narrative interview methodology combined with a photo elicitation exercise; both of which sought to encourage men to recount their experiences in narrative form. To achieve the goals of this study I carried out 30 interviews with a sample of 15 men in middle and older age with PD at various levels of severity. I also complemented this approach by collecting photographs exploring men's experiences of PD. Here I account for the methods used in this study, my approach to narrative interviewing and my sampling framework. I also discuss the approach taken to the analysis of qualitative data. I then conclude with a discussion of the ethical and reflexive issues arising in this study.

Study Background – the PROMS-PD study.

Before I begin discussing my research methods, I first describe its position within a wider research project. While carrying out my PhD I was a research assistant employed to manage the local site for the PROMS-PD research study (**PRO**spective study of **M**ood **S**tates in **P**arkinson's **D**isease). The study methodology, sample and results of PROMS-PD are reported in more detail elsewhere (for example Brown *et al* 2011; Hurt *et al* 2011; Gibson *et al* 2012). This project grew from the desire to investigate issues highlighted during clinical interviews pertaining to lived experience which couldn't be collected within the wider study design. Being part of PROMS-PD brought a number of benefits, including access to participants and a range of contextual clinical data. This data was used to develop the sampling framework described here and to provide important clinical and contextual data on participants. Contact with participants in PROMS-PD also meant I could build relationships with my participants in this study

over several years. This was undoubtedly a strength of the study, but also had a number of important implications. These implications are discussed later in this chapter and throughout the thesis.

Participant sampling

Participants were recruited from seven movement disorder and elderly care clinics acting as recruitment centres for PROMS-PD, located within the Merseyside and North West Wales regions of the UK. These sites covered a diverse range of geographical locations including busy inner cities, suburban towns and rural villages. All interviews took place over an 18 month during 2010-2011, during the 3rd and 4th years of the PROMS-PD study.

Because I hoped to capture as diverse a range of PD experiences as possible, and because I had access to contextually rich clinical and demographic data routinely collected in PROMS-PD, I first used this data to develop a maximum diversity sampling framework. At the first stage I highlighted 100 men, all the men in our local study cohort and categorised each individual according to their demographic and clinical characteristics (Appendix 1). Demographic data included age, age of PD onset and years since diagnosis. Clinical data included PD severity, derived from the Unified Parkinson's Disease Rating Scale (UPDRS), Hoehn and Yahr and Schwab and England rating scales (Hoehn & Yahr 1967; Schwab & England 1969). Cognitive impairment was recorded using the Mini Mental State Examination (MMSE) (Folstein *et al* 1975). Symptoms of mood disorder were extracted from the Geriatric Mental State (GMS) examination (Copeland *et al* 2002). I also included data on any medication side effects and motor fluctuations based on individual self-reports and my own observations. At the beginning of the project I sought permission from the PROMS-PD advisory group to

access this data. This framework ensured that I could capture individuals at differing stages of the disease, with a range of motor and non-motor symptoms and from a variety of social and cultural contexts without relying on the opportunistic, snowball samples commonly used in qualitative research to throw up such exemplars.

Description of participant sample

The 15 men I interviewed were identified by a systematic process using the PROMS-PD data. After identifying all the men in the local PROMS-PD cohort I then used the rating instruments listed above to reduce this list to 20 men, with another 10 men on a 'reserve' list. This list was drawn up using a constellation of symptoms to ensure I accessed people at a range of disease stages, with different symptoms and across a range of ages. Of the sample of 20 men I approached 18 individuals, 15 of whom agreed to take part. The three men who declined all did so because of poor physical or mental health. The final sample, including their major demographic and clinical characteristics is described in table 1. All men's names are pseudonyms. Biographical accounts for these individuals can also be found in chapter 4.

The mean average age of participants was 71 years (range 53-83). All men were of White British ethnic origin. No PD sufferers from other ethnic minority groups were available within the local study population, meaning none could be recruited. Average PD duration was 8.5 years (range 3-15 years). None were newly diagnosed; this was an unavoidable artefact of the study design, due to participants being recruited during PROMS-PD follow up interviews. Of the 15 men 8 displayed psychiatric symptoms and 10 experienced motor fluctuations in some form. I was unable to recruit anyone with the most severe PD, defined in this case as Hoehn & Yahr score 5 (Hoehn & Yahr 1967).

Pseudonym	Took photographs	Age	PD Severity (Hoehn & Yahr)	PD duration (years)	Motor symptoms (UPDRS)	PD motor fluctuations (Self report)	Non motor symptoms (GMS, self-report)
Bob	Yes	80	3	13	Tremor, rigidity, postural instability, slowness	Off periods	Depression
Simon	Yes	53	1	4	Tremor, rigidity	None	none
Henry	No	77	3	13	Tremor, Rigidity, postural instability, slowness,	Off periods. Dyskinesia's	Impulse control disorder. Incontinence
Tony	Yes	62	2	7	Tremor, Slowness	Off periods	Anxiety, depression
Harold	Yes	80	2	4	Slowness, rigidity	None	None
Tom	Yes	83	4	11	Tremor, slowness, rigidity, postural instability	Off periods	Impulse control disorder
David	No	71	2	9	Rigidity, slowness,	None	None
Ian	No	76	2	6	Tremor, rigidity, slowness, postural instability	Off periods	depression
Dafydd	No	73	2	15	Tremor, rigidity, slowness, postural instability	Off periods, Dyskinesia's	Hallucinations
John	No	66	2	3	Rigidity, slowness	None	None
Phillip	Yes	76	4	11	Rigidity, postural instability, slowness	Off periods	None
Hugh	Yes	67	3	11	Tremor, rigidity, postural instability, slowness	Off periods, Dyskinesia's	Anxiety, Depression, Impulse control disorder. Hallucinations
Peter	Yes	76	2	3	Tremor, slowness, rigidity	None	None
Albert	Yes	69	3	5	Tremor, rigidity, postural instability, slowness	Off periods	Anxiety, depression. Impulse control disorder. Incontinence
Roger	No	55	3	13	Tremor, rigidity, postural instability, slowness	Off periods, Dyskinesia's	Anxiety, depression, Impulse control disorder. Hallucinations

Table 1 Description of participants and their major characteristics

Given the extreme disability those at this stage of PD routinely suffer from, their ability to take part in research is limited meaning innovative designs are needed if we are to ensure their participation in research (Gibson *et al* 2004). I was also unable to recruit many people with young onset PD. This again was an artefact of the study design. Local service designs meant young onset PD sufferers were routinely referred to neurology services who were not involved in PROMS-PD. Instead PROMS-PD recruited from local movement disorder services, which had a higher preponderance of older service users. This means I struggled to access those with young onset. Of those three who declined to take part, two had young onset PD and no others were available from my original sample.

Justification of sample size

When PhD students ask supervisors about sample sizes in qualitative research, the answer they usually receive is 'it depends' (Baker & Edwards 2012). Many social researchers erroneously think that sample sizes are unimportant within qualitative research (Sandelowski 1995). However sample size is a necessary consideration in any qualitative study, with decisions being made depending on the epistemological and methodological basis of the research, the level of engagement with the data collected and ethics of the project (Sandelowski 1995; Morse 2003; Baker & Edwards 2012). After consultation with supervisors, experts in qualitative research and reviewing other phenomenological studies I decided to continue interviews until I reached theoretical saturation of themes (when no new categories or concepts emerge from the data) (Baker & Edwards 2012). The goals of this study were to capture a wide range of experiences, based on the issues men were willing to tell me about rather than what I felt was important. This did create a dilemma, between trying to ensure I captured a range of experiences, but while ensuring that interviews could be examined in

sufficient conceptual depth. I achieved theoretical saturation after 30 interviews with 15 men, because of the population I was able to access through local PROMS-PD sites, my reaching saturation of themes has important caveats, discussed later in the thesis.

Consent Procedure

Participants were initially approached at the end of their routine 12 month PROMS-PD assessment, in most cases during the third year of the project. Those showing an interest were then formally approached by letter a minimum of least three months later. This was a formal requirement of the PROMS-PD advisory group. Potential participants were then sent an invitation letter and copy of the study information sheet (appendix two). Participants were contacted by telephone two weeks later when they were given the opportunity to ask questions and asked to give verbal consent. If individuals agreed I then arranged to visit them at home to conduct the initial narrative interview. Before beginning any interview I took formal written consent including specific consent for the use of photographs, explaining that this also meant I could not guarantee their anonymity should any photographs be used (Wiles *et al* 2008).

Inclusion and exclusion criteria were the same as PROMS-PD. Participants had to be in receipt of a diagnosis of idiopathic PD in order to take part in the study. Exclusion criteria were:

- Presence of another neurological diagnosis inconsistent with a clinical diagnosis of idiopathic PD.
- Patients with severe sensory loss (hearing or vision) or communication difficulties that would interfere with the interview process.
- Insufficient understanding of written and spoken English to provide informed consent, or to communicate effectively within the demands of the study.

- Patients detained under the Mental Health Act.
- Patients judged unable to provided informed consent as defined by the Mental Capacity Act (2005).
- Patients judged too frail to cope with the demands of the study.
- Patients known to be involved in another study that would interfere with the present one, or who have expressed a prior wish not to be invited to participate in research studies.

Two further exclusion criteria were also included;

- Female patients.
- Patients residing within nursing care and/or residential care establishments at the point of recruitment into this study.

The goal of this study was to examine men's experiences, therefore women were automatically excluded. I also chose to exclude people living in residential or nursing care. This was because they were judged likely to have very different experiences given the communal nature of residential care environments (e.g. Ben Mortensen *et al* 2011). This assumption was reinforced in my interviews in which residential care was discussed as something many men feared. I made this choice because I felt that I would not be able to investigate these experiences in the required empirical depth that they warranted. Rather their needs would be better met in a separate research study with lived experience within residential care environments being a specific goal. Research on lived experience in residential care settings is even more necessary given the near invisibility of those living in residential care both within accounts of PD and indeed in wider society, meaning that research with these groups, and developing methods to access their experiences should be a priority (Milligan 2005).

Including those who are very frail is a particularly salient problem for research with older people, for people with severe chronic or life limiting illnesses or for those receiving palliative care (Wilkinson 2002; McKechnie *et al* 2007). Much debate has taken place about whether it is ethical for research to take place with those with severe chronic illness, or who are reaching the end of life (Casarett 2005). However, denying access for research to those for example in the later stages of PD means that we lack insight into their experiences, and therefore cannot provide truly person centred care sensitive to their preferences and needs. In this study, decisions about which patients were judged too frail to take part were taken as a consequence of the exclusion criteria of PROMS-PD, with decisions about whether participants were too unwell to cope with research being made based on the demands of that study. I do not take the position that research with those in the later stages of PD, who are not only often very unwell, but also may have significant cognitive or communication difficulties which make participant extremely difficult, should not take place (Bradburn and Maher 2005). Nor did I seek to exclude those at the most severe stages of PD, indeed in most cases they excluded themselves, withdrawing from PROMS-PD if they felt they could no longer cope with its demands. This indicates that rather than what is largely the current status quo in which those with severe PD are under-represented in research, we instead need to develop innovative, sympathetic and sensitive research methodologies, for example ethnographic or observational work, which can be used to gain the insights of those too frail to take part in traditional forms of research. Although not possible in this study due to the exclusion criteria of the wider PROMS-PD study, given the paucity of research into the experiences of those with advanced PD, further methodological and empirical work in this area should take place as a matter of urgency.

Ethical Review

Ethical review was sought using NHS ethical review procedures in 2008 (MREC number 08/H1003/131). Ethical approval was given by the Greater Manchester South Research Ethics committee. A copy of the approval letter can be found in appendix 2. Permission to access the PROMS-PD study cohort and data was granted by the PROMS-PD project advisory group. NHS R&D approval was sought from the Royal Liverpool and Broadgreen University Hospitals NHS Trust, Wirral Hospitals NHS Trust, and North West Wales NHS Trust. Annual reports were provided to these NHS Trusts as required.

Narrative interviewing and analysis

For this research I used an amended form of Wengraf's (2001) Biographical Narrative Interpretive Method (BNIM). BNIM is a detailed method for conducting systematic research into individual or collective lived experience. I used the BNIM approach as a means to conduct my interviews, with each person taking part in an initial narrative interview in which individuals were asked to tell stories about their experiences of living with PD. Narrative interviews were then followed up with a second semi–structured interview in which the initial narrative themes were explored in greater detail. In addition I used BNIM as a means to structure my interviews. However, rather than using the BNIM approach to data analysis, I instead used a narrative form of analysis drawing on the narrative approaches of Mishler (1986), Riessman (1990; 1993) and Labov & Waletzky (2003). I demonstrate an example of the data analysis process used in this thesis in appendix three.

Each narrative interview started with the same question designed to induce a narrative response;

In your own words, I would like you tell me about your general experiences of living with Parkinson's disease, and the problems that it has caused for you. *Please take as long as you like, I won't interrupt you while you are talking. Feel free to give me as much or as little detail as you want to. After you have finished, I might also ask you to tell me about how having Parkinson's disease has affected some more specific areas of your life.*

Individuals were free to choose where to start their narratives. Some needed prompting, or were hesitant in their initial statements. Where this happened I gave men prompts but also kept them purposefully vague, for example suggesting they 'started at the beginning'. During narrative interviews I tried to confine my responses to simply encouraging men to continue (Mishler 1986; Wengraf 2001). In some cases participants struggled with the narrative format, a known problem in narrative research (Mishler 1986). If my attempts to encourage narrative responses failed I switched to a more traditional semi structured interview format, but tried to encourage responses in the form of narratives whenever possible. Fortunately I only had to revert to a semi structured approach to interviewing in two cases (Peter and John). After men's stories based on this initial narrative concluded, I then gave people a short break, during which I reviewed my field notes, before then asking further narrative oriented questions, with the goal of further elucidating narrative responses.

At the conclusion of each narrative interview I asked participants if they were willing to take part in a second semi structured qualitative interview and the photo elicitation exercise. All participants agreed to take part in a second interview, although David sadly died before this could be carried out. Interviews were carried out between 1 and 4 months later. Second interview schedules were then developed after a preliminary analysis of each person's data. Second interviews were shaped by the initial interview and therefore differed substantially from each other. For those taking photographs the interview usually started with a discussion of their photographs before moving on to

the wider interview. With the participant's permission, all interviews were recorded on digital audio recording equipment before being transcribed verbatim. Due to his often severe problems with speech, my interview with Phillip could not be recorded, so instead I relied on field notes and photographs for his data. I also recorded detailed field notes of my own thoughts and reflections at the end of each interview. Field notes were a crucial first stage of my analysis, in which early issues emerging from interviews were discussed. They also enabled me to reflect on my own role in the research process as the study progressed (Emerson *et al* 2011). By the end of the interview process I had carried out 30 interviews. Of the 15 men I interviewed, 13 completed 2 interviews. David died before his second interview could be carried out, meaning only a single narrative interview took place. I also carried out three interviews with Simon, who due to both time constraints and the depth of information Simon gave about his experiences, meant that I conducted two separate narrative interviews with him.

After interviews had been transcribed, I used a form of member checking in which copies of transcripts to all participants. Transcripts for the narrative interview were sent prior to my second semi structured interview to give participants the chance to review the transcript and discuss any issues at the beginning of their second interview. Transcripts for the second, semi-structured interviews were posted after the second interview, with an invitation to contact me by telephone or to speak to me during their PROMS-PD assessments if they had any issues or comments. In most cases men did not respond, however Albert and Simon both made many comments. In Simon's case, reviewing the transcript forced Simon to become aware of many important issues in his account, including how his comments could be assumed to give an overly negative portrayal of his illness. Albert returned numerous comments expanding upon his

points or clarifying others, and also made numerous telephone calls to further clarify his issues. This form of member checking proved immensely useful in my analysis. In addition to sending transcripts to participants, I also discussed the content of transcripts with my supervisors and with other postgraduate students during informal data analysis seminars held at Liverpool University. These sessions gave me the opportunity to share my data with others, who could act as 'critical friends' regarding their content and my analysis.

Photo elicitation methodology

This study also used a photo elicitation methodology (Harper 2002; Hergenrather *et al* 2009). Photo elicitation techniques have particular use in health research on men and masculinity (Oliffe & Mroz 2005; Oliffe & Bottorff 2007). Here photo elicitation techniques can give men the opportunity to describe experience through empirical examples rather than relying on what can be often abstract concepts (Johnson *et al* 2011). Photographs can also orient men towards the embodied nature of health and illness states by giving examples of their actions. Indeed as will be seen, the most common form of photograph was of the various hobbies, pastimes and other forms of physical activity men took part in; a means of communicating what they could do. Using photographs also gave men control of their discussions, allowing them to talk about what was important to them rather than to me (Oliffe & Bottorff 2007; Thompson *et al* 2008). As such, photo elicitation techniques provide a powerful complementary perspective to phenomenological and narrative research; giving men specific examples around which narratives could be told. This method was broadly successful but with some caveats which I discuss at the end of this thesis.

Photo elicitation; collection and analysis of data

I asked all 15 participants to take part in this stage of the project. Participants were free to choose whether to take photographs, what photos to take and when and how to take them. Those who chose not to take part in the photo exercise were free to continue with the wider interviews. After the initial interview I gave each man a disposable film camera and operating instructions, and asked them to take photographs of their experiences. Disposable film cameras are easily portable, inexpensive and do not require any technical knowledge or other equipment to operate. Some did choose to take photographs with their own equipment. Where men did this I arranged collection of photographs before our second interview. Cameras were then collected and developed with participants being given copies at the beginning of their second interview.

Nine of the fifteen participants took part in this stage. Of those six that didn't one (David) died after the first interview and one (Dafydd) refused outright. The remaining four either forgot or felt they had no experiences worth photographing. Overall I received 150 photographs, with people taking between 8 and 42 photographs each. Several also chose to include photographs from earlier in their lives, for example past holidays or pets which were also included in my analysis. I included these photographs in my analysis; when photographs were taken was less important than their role in conveying personal meaning. However in other forms of photo elicitation such as photographic diary techniques such inclusion may cause difficulties (Drew *et al* 2010).

Photo elicitation methods are undoubtedly a useful form of data collection but also give rise to a number of further ethical and reflexive dilemmas (Drew *et al* 2010). I faced one dilemma about how much detail to give the men about the photos I wanted them to take. I consciously tried not to give detailed descriptions about what to take as this could 'lead' participants to simply (re)produce what they felt I wanted. I

purposefully gave vague descriptions of its goals; that I wanted photographs of experiences in their everyday life that were important to them. However in two cases this resulted in their only reproducing subjects discussed in our initial interview. It was clear that some men needed more support than I gave, which may account for the fact that four men either forgot or did not think their experiences were worth recording. How we describe the purpose and goals of visual methodologies therefore requires specific consideration (Guillemin & Drew 2010).

Narrative analysis of data

I used a narrative form of analysis adapted from Riessman (1990; 1993) and Mishler (1986) to interrogate my qualitative data. Transcripts were read multiple times. A first, 'quick' reading gained a general feeling for the transcript, its tone and its major issues. A second reading developed a series of biographical accounts summarising the major stories within each interview (appendix three). The substantive analysis began with a third, more detailed reading. Stories were identified and separated from the wider transcript. Rather than translating stories into simple themes I wished to remain as close as possible to the content of narratives. I therefore used an approach which allowed this close connection to the data and the content of men's stories to take place.

My approach to analysis draws upon an approach discussed by Mishler (1986) and Riessman (1990; 1993). Using templates within Microsoft Excel, each narrative was broken up into what Riessman describes as five constituent structures of narrative. The ***abstract*** is initially told in order to describe what a story was about; orienting the listener to the storytellers place, time and personal situation. The main body of each story was the ***complicating action***; a series of statements moving the plot on and

telling the listener what happened in their particular story. Following the complicating actions, most stories had an ***evaluation.*** The evaluation seeks to move the story on, providing a break between the complicating actions and moving towards the result of the story. This result is the ***resolution;*** the root of the story and point the narrator is trying to convey, containing the narrators' judgements about their feelings about the impact of an event. Finally most stories finished with a ***coda***. Codas are not necessarily present in all narratives, but serve to bring the story back to the present, making clear its relevance to the person and their current life.

The first stage of this process was to identify the stories men told in their transcripts. Stories took two forms; the grand-narratives present throughout the interview, and the range of sub-stories; stories of particular events, experiences or phenomena contributing to their wider narrative (Frank 2000). Using the above structure, I then examined how each of the narratives were assembled in relation to the wider aims of the study, namely the lifeworlds of men with PD, the relation of their lived experiences to gender and ageing, and the consequences of changes in the lifeworld for medical practice.

My prolonged contact with participants along with the often detailed stories they told of their condition meant I collected much more data than expected when the project was planned. As a result I was unable to conduct such a detailed analysis for all 30 interviews. I therefore selected a sub sample of 5 participants (Bob, Simon, Tony, David, Roger). Representing a cross section of the wider sample, and exemplars of particular lived experiences in PD the 10 interview transcripts for these five participants were then analysed in their entirety using the above structure. Once completed, I then wrote detailed accounts of the meanings of each narrative, using these to develop simple thematic titles for each. Titles sought to summarise the

central theme of a narrative, enabling them to be clearly categorised and linked to each other. Examples of thematic titles included: *walking, cleaning, feeling depressed,* or *feelings about the future.* Once this was concluded, titles of relevance to each other were then grouped together. These themes were refined through an iterative process of revisiting the narrative templates and their contents, leading to the development of five overall categories of relevance to the aims of the study. These categories were *everyday embodied practices; time and temporality; coping strategies and resources*; *ageing* and *masculinity.* These five themes formed the basis for my results chapters. Once these themes had been developed all the remaining interviews were then analysed using the same analysis techniques, but with the analysis being focused upon stories that reflected these five categories.

Photographs were also integrated into the wider narrative interview analysis. I was as much concerned with how men used photographs as part of their wider narratives as I was their content. I found that men usually told stories about their photographs; what was going on, why they had taken it and what relevance it had to their lives. Based on this I used a similar technique to analyse any photographic data. Sections of transcripts where photographs were discussed were again separated into the five narrative structures described above before being analysed using the five analytic themes emerging from my wider narrative analysis. Photographs were also examined in terms of their visual and wider context. Through this, photographs were revealed as an empirically rich source of narrative data supporting men's wider stories of PD.

Summary

This project uses a qualitative, multi-method approach combining narrative interviewing with photo elicitation techniques. More widely, the collection of data was

also supported by the detailed quantitative data collected as part of PROMS-PD. This is a particular strength of this study, in which a sample could be designed which captured as wide a range of PD experiences as possible. Narrative interviewing, when combined with photo elicitation methods provides a useful means of accessing both lived experiences and the practices contributing to these experiences. Using such an approach had its problems and pitfalls, not least the unexpectedly large amount of data I eventually collected and difficulties in integrating textual and visual data. But ultimately this approach enabled me to gain access to an empirically rich source of emplotted data about PD's lived experience.

Part 3. Ethical and reflexive considerations

I now conclude this chapter by discussing the various ethical and reflexive concerns faced in this research. Bracketing; the separation of personal perspectives and judgements to remove them from the analysis is a central but contested part of phenomenology (Paley 1997). More recent phenomenological developments have taken the position that we cannot 'bracket' our personal prejudices and standpoints as required by Husserl's original conception (Gadamer 1989; Dowling 2007). Rather we should focus on a reflexive interpretation of our personal standpoints and how they contribute to our research perspectives. Here I discuss the reflexive concerns emerging during this study. It is also important for us to consider the ethical considerations arising in research. Many of these concerns are common across all research involving human participants; others are specific to research with men, older people, or with chronic conditions. I discuss each of these concerns in turn.

Ethical concerns

My primary concern in this study was the stories men told about their own illness. This raised a number of practical and ethical dilemmas. It is often thought that qualitative research is essentially harmless. However, although not dealing with direct clinical interventions and their potential for harm, qualitative research does have the potential for psychological or emotional harm. As researchers we occupy privileged positions; able to access often deeply personal narratives of suffering. But we must also consider how in encouraging people to disclose these narratives, we can lead them to talk about what can be often distressing experiences. I was often surprised with the range of often distressing issues that the men were willing to describe. On more than a few occasions I faced men who became tearful, upset or angry when discussing their experiences. Some grew angry at my lines of questioning, even when they were predominantly in control over interviews. Narrative requires people to assemble incoherent experiences into a meaningful plot, often for what was the first time. A variety of experiences can come to make sense, but this can also make people realise just how disabled they had become or just how bleak the future was. For some of the men the narrative interview was the first time men gave form to these experiences, coming to realise just how badly their illness was affecting them. Such emotional expressions could be difficult for them and for me to deal with (Bennett 2007). It is therefore important for researchers to have means of dealing with such events when they happen. In this study participants retained control over their narratives and could choose what to or not to discuss. Therefore they only found themselves recounting distressing experiences if they chose to do so. Those who found any stories too upsetting to continue were free to stop. Indeed several found themselves reaching a point where continuing to talk about an issue did become too upsetting, for example when talking about depression, about the growing likelihood of care, or talking about particularly distressing experiences of PD symptoms. Where this happened, I accepted

men's desire to close down their stories, but also gave them the opportunity to either retell these stories in a less distressing form, or to continue if they felt it was an important story to tell.

If people became very upset during the course of the interview I offered to cease a line of questioning and in some cases terminate an interview. Although I offered to do this on several occasions none of the men chose to do so. If during the course of interviews men became distressed, needed further advice or had questions about their illness that I could not answer (either because I did not know or because it would be unethical for me to do so) I ensured I had contact details for support services which I could pass on (e.g. those organised by Parkinson's UK) or I would encourage them to speak to their health professionals, most often their local PD specialist nurse if available. In any cases of truly distressing experiences, or in cases where they came to realise they had a problem (such as in impulse control disorders) I suggested people contact their GP's, consultants or PD specialist nurses. GP and consultant contact details were routinely collected as part of PROMS-PD meaning that if any were at risk of imminent harm (e.g. suicidal thoughts) then their GP's or consultants could be quickly contacted. This proved unnecessary during my PhD interviews but did happen on several occasions within the wider PROMS-PD study.

As noted already a further key ethical and reflexive issue concerned my past contact with the men. I had usually interviewed these men 3-4 times over a 36 month period prior to these interviews. This had a number of benefits, but also led to numerous ethical issues. My previous interviews were clinically driven, asking many pre-determined questions about presence and severity of symptoms or about their response to treatment. Based on our prior knowledge of each other many came to assume that I was a medically trained expert in PD. During interviews I would be

frequently asked about existing treatments, or the potential for future treatments or cures. More significantly I would also be asked about individual care. I do not come from a health services background and am not medically trained. Given my position as a researcher rather than clinician it is unethical and potentially even dangerous for me to give participants medical advice about their treatment. Such a statement is obvious but becomes complicated when participants, often lacking easy access to information about their illness regularly asked me questions about PD. It can cause practical issues relating to rapport but more importantly is also unethical not to honestly answer these questions if it is possible to do so. In practice I attempted to answer any questions I could but restricted my answers to generalities; the general disease course or general characteristics of medications. In addition I explicitly stated that I could not give advice about individual care. If any specific medical information was requested I encouraged participants to contact their clinical care teams for further advice.

The use of photographic elicitation methods also gave rise to specific legal and ethical concerns (Prosser 2000; Wiles *et al* 2008). Participants were given the freedom to choose when and where to take photographs. But taking photographs could also expose them to specific ethical and legal difficulties. For example Albert described difficulties in gaining consent when attempting to take photographs of his health professionals. Given their central importance in the men's lives, it was not surprising that the men wanted to take photographs of their medical encounters. Initially naïve to how significant a problem this could be, but also not wanting to restrict their choices I gave less guidance about the potential problems participants could face than I should. This indicates a specific practical issue that researchers have to consider when using visual research methods; the difficulties of taking pictures involving other people, and the anonymity, confidentiality and consent issues this raises (Wiles *et al* 2008).

More widely considered within visual research are the difficulties in maintaining participant anonymity. Transcripts can be relatively easily anonymised using code numbers, pseudonyms or by removing identifiable data, as I do here. Photographs are harder to anonymise. In many studies photographs are edited in order to preserve anonymity, e.g. by removing faces (Oliffe & Bottorff 2007; Wiles *et al* 2008). But in anonymising photographs in this way we can often lose the richness that makes them such a strength. In addition, because of the way many used photographs to discuss their difficulties and also because of the visual nature of many of PD's symptoms I could not easily anonymise men's photographs. The face and body were sources of data themselves, being sites in which PD manifests itself; for example photographs illustrating a stooped posture or facial masking (Tickle-Degnen & Doyle Lyons 2004). Given the empirical richness of visual research data, it runs counter to this method to purposefully deny access to relevant visual data (Wiles *et al* 2008; Sweetman 2008). My approach to this problem was that in such cases where anonymity could not be guaranteed I would seek express explicit permission to use photographs (Pink 2007). Explicit written consent was taken at the beginning of my interviews, while verbal consent was also sought where possible whenever any photographs were used publicly, for example in presentations. The implications of giving permission to use visual data were also carefully explained at the point of consent in order to ensure that participants were fully aware of these issues. After receiving this explanation only one person (Dafydd) refused outright, in his case in order to retain his privacy. Finally all photographic data was kept under the same conditions as transcribed data as per the requirements of the data protection act (Wiles *et al* 2008).

Reflexive concerns

It is also important to discuss the reflexive issues arising from my position as a researcher, and as a man and how they may affect the interpretations made within this study. To do so I draw upon the work of Robertson (2006a) who reflected on how his own position as a man shaped his research, in order to do the same regarding my own position in relation to the men I interviewed. First I account for how I became interested in the subject of men's experiences of PD and their relation to masculinities. Originally trained in human geography, my interests in gerontology grew through a number of research projects conducted prior to and during my PhD. I had worked as a research assistant on several studies looking at differing elements of the experience of dementia, which led me to develop an interest in the lived experience of illness in older age. The inspiration for this project emerged during my first year of interviewing PD patients as part of PROMS-PD. This study involved asking numerous questions about PD's symptomology, in order to grade symptoms according to pre-defined rating scales which could then be subjected to statistical analysis. However I was struck by the depth of the accounts people gave me, and how richly they described their own experiences, experiences which were largely ignored within the PROMS-PD study methodology. In addition I was struck both by the sheer number of men I was interviewing, and the various accounts they gave about their illness. Upon reviewing the existing literature in PD, it became clear that, unlike in my previous research into dementia in which a large literature examining dementia's subjective experience has developed, (often referred to as the 'social model' of dementia, or a personhood approach to dementia (Kitwood 1997; Downs 1997; Bond and Corner 2001), such an approach has not been widely applied to PD. In addition, and as discussed in chapter 2 despite the epidemiological literature indicating that PD predominantly affects older

men, few studies had specifically considered PD as a 'gendered' illness; not only how men experienced PD, but the various resources, including gender and masculinity, that were used to negotiate this lived experience. This gap, alongside my previous research interests, led me to take on this thesis and adopt the approach taken here.

Given the failure of the medical literature in PD to adequately consider PD's lived experience or how this experience is influenced by gender, I adopted a predominantly sociological and gerontological rather than biomedical or clinical perspective. But I also had to demonstrate how my study was relevant to PD's routine clinical treatment; that it answered the 'so what' question. To do this I needed to demonstrate how my approach is relevant to the 'real world' problems faced by men with PD, including its routine treatment. To do this I chose to examine how an understanding of PD's lived experience can contribute to the design and delivery of PD services. Therefore showing how a sociological and gerontological orientation to older people's experience could be used to inform a study of PD, and which would also be clinically relevant was a key initial concern. I achieved this through careful attention not only to the literature but also my own perspectives and how these might steer me down particular courses away from its relevance to service provision.

I found that my personal position as a man, and as a young man in my early 30's informed all stages of this work, from my sampling, to how my interviews were conducted to my analysis, and to my own sensitivity to the men's experiences. I kept reflections of my experiences of interviewing men in my field notes; this is something I have learned to adopt in the future (Robertson 2006a). First I consider my own position as a younger man, and how this shaped my judgements about ageing. Although I sought to engage with the fact that many of these men were ageing, I did not want to engage with any stereotypical assumptions about older men or older age.

Rather I sought to investigate how men engaged with popular stereotypes of ageing themselves. But so ingrained are these stereotypes in popular culture that this can be difficult in everyday conversation even for gerontological researchers (Bytheway 1995). My own age also played a role, creating the illusion that I was a student, or even in some cases a grandchild type figure. I found such assumptions to be a useful means of gathering data, and in several cases used this to my own benefit, for example encouraging men to tell long and detailed stories. I also found that men's judgements about me could also steer the nature of my interviews; many men seemed to be surprised that 'members of the younger generation' were interested in their lives, while most frequently most assumed I was a student (rather than also being in paid employment as a researcher alongside my studies). I certainly found this position more useful than that of being seen as a medical professional, an identity I sought to distance myself from, but which could be difficult given my prior contact with people as part of PROMS-PD. Others were grateful that 'people like me' (seeing me as a 'medical scientist') were seeking to improve their situation by trying to cure PD. Of course this was a goal outside the remit of this work, my work being more concerned with 'care' rather than 'cure'. These issues all positioned myself in relation to the men I interviewed, it is important to be clear of the role this plays in the data collection process.

In the research literature, talk of research conduct usually concerns the powerful researcher and powerless respondents (Oliffe & Mroz 2005). In practice the boundaries I faced were not so clear cut. Research with men can complicates these issues between powerful and powerless, not least as men, in the process of the interview (and of course including myself) seek to negotiate the power relationships implicit within qualitative research, and also forming wider social relations (Oliffe &

Mroz 2005; Oliffe & Bottorff 2007). A narrative methodology seeks to give participants much more control over interviews than might take place in more traditional semi-structured approaches to interviews, something many sought to grasp, but that others could struggle with, not thinking that their experiences were significant (Mishler 1986). Peter was an example of this, who struggled to recount his experiences of PD in a narrative account, in his case because at least in his initial interview he judged PD as little more than an inconvenience. Others sought to take control of the interview and the opportunity it gave them, something I was happy to allow, however at times this could cause issues. Several of the men used their own authority and status, usually associated in their working life to position themselves in relation to me within the interview (Seale & Charteris Black 2008). This was exemplified by Albert, a former senior lecturer in biochemistry often tried to turn my interviews into 'lectures' on the biochemistry of PD, with Albert frequently resisting my subtle and sometimes not so subtle attempts to steer him 'back to topic'. However both Peter and Albert's accounts show how these accounts were also emplotted; Albert' 'lectures' and Peter's giving little significance to many of his problems gave me fascinating insights into their wider lived experience and how they used these experiences to negotiate PD (Mishler 1986). Therefore such issues had implications for my data collection, and how I positioned myself in relation to the men.

My position as a man also brings my own interpretations of the data (Rimmon-Kenan 2006). I engaged with many of the men, and they with me in a form of 'blokeish banter'; a form of small talk to break the ice, but which formed gender appropriate, even gender stereotypical forms of interaction (Oliffe & Mroz 2005). For some men this occasionally took on an aggressive and even sexualised nature, although given that most of the men saw this as an element of their past this was relatively rare. More

commonly men (most commonly Roger) swore or used aggressive language to convey the emotive power of their experience. In order to communicate the power of these statements such instances are recorded verbatim. My own male status will have also shaped how I responded to these situations and my subsequent reading of the interviews. It is likely that I am myself more likely to engage with what can be seen as male appropriate forms of emotional expression (Oliffe & Mroz 2005; Robertson 2006b). Several men promoted their own sporting interests, for example Tom's gave a detailed account of his interest cycling, while David spoke in detail about his love of hiking. Both of these are also pursuits I take part in, giving me a shared interest upon which to built rapport, but which may also shape how I prioritise these accounts (these accounts feature prominently in the following chapters). Accounts of activity are an important part of masculinity and ageing, demonstrated in the literature on masculinity (e.g. O'Brien *et al* 2005; Tulle 2008). However in focusing on such activities, the question becomes; instead of challenging do I reinforce or reproduce the importance of activity to hegemonic forms of masculinity (Robertson 2006a)? As the men, based on being men, prioritised certain accounts of experience, I am also likely to prioritise these same acts. I tried to manage a potential masculine reading or even masculine prejudice in my data collection and analysis, for example in discussions with one of my supervisors and by sharing data with other postgraduates (most of whom were women, and who often had very different readings of my data) during local 'data analysis sessions'. But my own masculine position will have contributed to my interpretations of the data, meaning my own implicitly gendered approach to the data about men's experience, and how this may challenge, reflect or reproduce predominant 'hegemonic' forms of masculinity within the research interview must also be considered. As Robertson (2006a) points out, there are rarely right or wrong answers to such questions, however it is important for any researcher to reflect on

such questions and what they may mean for the findings of research. Doing so represents a bringing to the foreground of reflexive issues, rather than ignoring their significance to any research endeavour.

Conclusion

In this chapter I have described the theoretical background to this study. Through the use of narrative methodologies I explore men's experience of a changing lifeworld in PD. By using a narrative approach I hope to gain access to the stories men told of their lives and the experiences that are shared through these stories. Narrative also gives us a means to access the various resources men use in interpreting their illness. I therefore examine how ageing and masculinity are emplotted within men's narratives, and therefore how PD's lived experiences are shaped by these two practices.

Chapter 4. Interview Participants

Here I introduce the men I interviewed, the characteristics of their PD and some of the major issues arising from their interviews. All interviews took place in 2009-2010. All names are pseudonyms.

Bob was 80 years old, and had suffered from PD for 13 years. Bob was married but lived separately to his wife, who because of her ill health had to live in residential care. He saw his wife regularly but found the separation upsetting, often feeling very lonely on his own at home. A former electronics engineer, Bob enjoyed tinkering and doing DIY around the home, restoring classic cars and gardening. Bob was also house-proud, having extensively renovated his home over the years. A long standing member of the Rotary club, Bob had an ethic of "service above self", and frequently sought to help his neighbours. Bob's PD was moderate in severity, with tremor being his most significant motor symptom. Bob also experienced frequent bouts of depression, occurring throughout his PD, but which Bob described as being due to his loneliness at being separated from his wife. Bob struggled to talk to me about his depression and how he felt during periods of depression. Bob also thought that many of the difficulties he faced due to PD were to be expected given his advancing age.

Simon was 53 and was the youngest man in the study. Simon had suffered from PD for four years. His PD was relatively mild, with tremor currently being the most significant symptom. He also found himself struggling to walk long distances, and suddenly and inexplicably feeling very fatigued. Simon had always been physically active; enjoying many adventurous activities, but had been forced to give most of these activities up. A father of two, Simon had recently been widowed; his wife had died recently after a long period suffering from early onset Alzheimer's disease. Simon saw himself as

active and able to adapt, now applying the skills learned from looking after his wife and autistic stepson to his PD. Simon also had problems with depression and anxiety, which he managed by constantly being mindful of his feelings. A former rigger in a boatyard, Simon no longer worked and was on long term incapacity benefit. Simon did not expect to return to work in the future. During my interviews, Simon had moved home, and was seeking to start a new life in his new surroundings. However Simon felt his PD was likely to limit just how far this new life could be achieved. Simon made a point of showing how he responded to his PD, trying to find as much about his illness as he possibly could in order to find 'coping strategies' which he could use to help deal with his current problems, and which could help him prepare for what he felt was an uncertain future.

Henry was 78 and had suffered from PD for 13 years. Henry's PD was growing more severe; in addition to facing all of PD's major motor symptoms, he also experienced both dyskinesias and off periods. Experiencing frequent bouts of incontinence, Henry had chosen to be catheterised. Henry also experienced frequent bouts of impulsiveness; what he described as 'doing too much'. Aware of the difficulties this caused with his wife, Henry tried to be mindful of his seemingly increasing impulsiveness by trying to consciously manage his impulses and desires. Despite his numerous problems, Henry saw himself both as an expert on PD's lived experience and an exemplar of living well with PD. He sought many opportunities to share his experience with others with the illness, such as volunteering for Parkinson's UK, taking part in research, and donating his brain (upon death) to the Parkinson's UK Research Brain Bank. However he recently had to give much of his volunteering duties up as it was becoming too much for him to manage. His PD worsening, Henry found himself thinking more and more about what PD would mean for his future.

Tony was 62 and had been diagnosed with PD in his mid-fifties. Tony also had a history of mental illness stretching back a period of 15 years. Tony's PD was moderate in severity, and could be seen in difficulties with tremor and physical slowing. Tony also noted that PD was reducing his physical strength and stamina, which make it increasingly difficult for him to continue with many physically active hobbies such as sailing or riding motorcycles. Suffering what he called a 'nervous breakdown' in the mid-nineties, Tony still suffered intermittent periods of depression and anxiety, but through medication and regular counselling could manage these problems in his everyday life. However, now his PD was beginning to overtake these mental health problems as the dominant feature of his life. In the years since his nervous breakdown Tony had left employment, divorced his wife and moved to an isolated part of North Wales. Tony was aware of his PD worsening and that his medications were being increased more rapidly. This experience left him wondering 'how long he had left' and what he would do when his PD got *'bad, bad bad'*.

Harold was 81 but had only had PD for four years. Sporty for most of his life, PD was most noticed because it was beginning to affect his sporting activities with friends. PD was slowing Harold down, which was also beginning to cause him difficulties in getting around and in doing activities of daily living. A widow for ten years, Harold felt he had recovered from this period of mourning, and was now proud of that he had learned look after himself, and of how much he could still do. Harold regularly travelled nationally and internationally, regularly visiting family in the United States and regularly flew there to see them. Harold also regularly drove long distances to see his sister in the North West of England. However Harold was becoming less active in his local area, struggling to walk around the shops and parks in his local area. Harold

socialised regularly by playing sports with a group of friends of long standing, however he was now finding that he struggled to compete with his friends.

Tom was 83. Having had PD for 16 years, Tom was one of the most disabled men in this study. Tom struggled to walk, could no longer leave the house without the assistance of family, needed a wheelchair when outside and struggled in his ability to get around the home. Tom was also extremely slow physically and mentally, and could find himself becoming increasingly 'fuddled' and confused about his everyday tasks. Tom also experienced motor fluctuations, hallucinations and a sense of feeling emotionally 'empty'. All this meant he now struggled to complete even basic everyday tasks without help. However Tom also made a point that there were some things he could still do, and that he could still find ways to solve his problems. A keen cyclist for most of his life, Tom could still ride a bike, albeit indoors by using an indoor trainer. Cycling gave him a way to remain physically fit and supple; which he felt could slow down his PD. However despite this, Tom felt his PD was gradually becoming too much for him and his wife to manage. Tom expected to have to move into residential care soon, and worried about what this would mean for him.

David was 70 at the time of interview and had PD for 9 years, having been diagnosed in 2001. At the time of interview David was also suffering from bowel cancer but at the time expected a good prognosis. However a few weeks after my interview and during what was thought would be a routine operation, David developed complications and subsequently died on the operating table. David's PD was characterised by tremor, muscular stiffness, physical slowing and rapid fatigue. A former Head Teacher, David had hoped to have a physically and mentally stimulating retirement, but now struggled with many of these activities. David had been widowed 10 years previously but did not speak about this in detail. A keen amateur painter, David no longer had the dexterity

required to paint to his past abilities. David was also a keen hill walker but had found himself having to increasingly scale back his activities. In a strange experience for him, David had also developed a compulsive gambling habit earlier in his PD, losing money on slot machines, something he had never done in the past. He had managed to stop his gambling by managing these impulses. At the time of my interviews David was considering moving from his large family home into a smaller property he could more easily manage.

Ian was 76 but looked surprisingly young for his age. He had suffered from PD for six years. with his symptoms appearing to progress rapidly. Ian's main symptom was tremor, but unlike the norm, Ian's tremor responded only poorly to medication and was uncontrollable for much of the time. As a consequence, his tremor got in the way of even basic daily activities; cooking, dressing and eating. A former Handyman, Ian now struggled with the upkeep of his home, lacking the strength and motivation to keep on top of it. In my earlier interviews with him Ian had always been upbeat and jovial. Since losing his wife to Alzheimer's 18 months ago Ian still appeared to be in mourning, which also seemed to heighten his sense that life was growing harder and harder to cope with. Ian was struggling to cope with his daily life, blaming his children for not helping him more than they did, but also getting angry at them if they did try to help. Given his current difficulties in coping, Ian worried about how he would manage in the near future.

Dafydd was 74 and had experienced PD for 15 years. Dafydd's PD, although severe was at the time of interview being well managed. In particular, Dafydd's medication regime was working very well, enabling him to continue with many of his activities. Dafydd found the extent to which his medications were working itself surprising, claiming that his doctors had him on a good 'cocktail' of drugs. Dafydd experienced

most of the motor symptoms of PD, along with dyskinesias and off periods. However he felt able to tolerate these problems, his medications keeping them under control for most of the time. Dafydd was generally positive about his condition and particularly about the care he received from his doctors. Although he had been forced to give some activities up, and do others less Dafydd made a point of trying to remain as engaged as possible with friends, family and his activities. Dafydd also described himself as living for his grandchildren. Dafydd described finding continual ways of adapting to the limitations of his condition, but over time was finding this gradually becoming harder to manage. In my last contact with him he withdrew early from PROMS-PD, finding that his condition had worsened and he was now struggling to cope.

John was 66, and had been newly diagnosed with PD at the start of the PROMS-PD study in 2007. John found himself slowing physically and increasingly mentally, and also showed signs of muscular rigidity, symptoms including drooling, facial masking and slowness in physical movements. Unlike most of the men in this study, John still worked, continuing to work at a shipbuilding company despite being older than the statutory retirement age. John was supported in continuing to work. John spoke of work as a 'hobby'; he worked because he wanted to (rather than needing to), because he felt needed and because he enjoyed the social world of the factory floor. John claimed his PD was having little impact on his life, although his wife thought it had greater effects than John was willing to admit. John found himself struggling with some hobbies and sports, but had chosen to give them up rather than struggling on with them. If he couldn't compete, or couldn't do them to the best of his ability he didn't see the point in continuing. John described himself as being unemotional, although his wife felt his PD affected him emotionally more than he was willing to discuss with me.

Phillip was in his seventies and had had PD for 14 years. Phillip's PD had progressed significantly, so much so that 18 months before my interviews he had undergone a form of neurosurgery called Deep Brain Stimulation to treat his condition. Phillip's PD severely impacted on his speech. Saying more than a few words or sentences required a great deal of effort, while Phillip's voice was extremely slurred and quiet, so much so that my interviews with him could not be recorded. Phillip's PD could fluctuate wildly. When 'on' he could walk around and do many things, for example doing light gardening. However he also suffered from daily, severe off periods, usually commencing in the early afternoon. Almost all Phillip's activities had to be carried out in the mornings, in the afternoon he could do little more than sit in a chair looking (rather than watching) at a TV. These problems had improved somewhat since his operation, but were once again slowly growing worse. Phillip's PD was extremely distressing for his wife, who struggled to look after him in the afternoons and to sleep at night as Phillip moved, punched and kicked out in his sleep. Phillip still remained hopeful that his doctors could find some way of dramatically improving his symptoms. Mostly, Phillip hoped to play golf again someday.

Hugh was 68 and had been suffering from PD for 11 years. Hugh suffered from significant degrees of tremor and physical and mental slowing. Hugh also described experiencing often dramatic motor fluctuations. Not only limiting his activities, Hugh was also acutely embarrassed by many of his PD symptoms. Most severe for Hugh, his condition would change markedly and suddenly, often at unpredictable times. The result of many of these experiences was that Hugh found himself withdrawing from many of his activities. Hugh found it difficult to both continue with his activities, and also worried about how his symptoms appeared to those around him. Embarrassment about how his body looked as much as his physical difficulties caused Hugh to

withdraw from many of his activities. Hugh also struggled with periodic bouts of depression and had problems with impulsively spending money, gambling, and falling foul of a number of postal scams. With the support of his family, Hugh now struggled to manage these desires.

Peter was 76, and had had PD for three years. Peter had experienced growing problems with walking and also noticed tremor was increasingly getting in the way of his activities. Peter generally regarded his PD as a nuisance and inconvenience, something which 'got in the way' rather than something that had dramatically changed how he lived his life. In a relatively rare experience, Peter described feeling significant amounts of pain, caused by muscle stiffness and spasms. Peter described himself as a member of the 'positive mental attitude club' and tried to use this approach to his PD, showing that he would not let it 'beat him'. Peter felt that it was other difficulties in his life rather than his PD that were causing him greatest difficulty. Peter lived with his wife who also had her own health difficulties, meaning that to some extent they both had to care for each other. Over time, Peter was finding that his PD was becoming something more distressing as his symptoms worsened.

Albert was 69 and had suffered from PD for five years. His PD was progressing rapidly, and was limiting many of Albert's activities. Albert's PD was akinesia dominant, leading to problems with balance and walking; Albert now needed to use walking sticks and frames whenever outside. Albert also experienced changes to his mood and changes to many of his desires, including sexuality, but was not sure whether this was a 'normal' result of age or due to his illness. A former biochemist, Albert took a very particular approach to his illness; one defined by scientific interest. Albert frequently experimented with medication regimes rather than taking them as prescribed, and challenged the abilities and knowledge of many of his clinicians; often feeling that he

rather than his doctors knew best. He also tried to use his past academic contacts to research his condition. Albert found his responses to his PD to be entirely rational, but his family claimed that they were increasingly struggling to look after him, especially finding it difficult to manage his seemingly increasing impulsiveness. Albert's wife, friends an family were becoming increasingly worried and exasperated by Albert's increasingly impulsive behaviour, his unwillingness to listen to them, and his increasing sense of frustration.

Roger was 56 and had experienced PD since his late 30's. Roger's major motor symptoms were tremor, rigidity in the muscles and difficulties with walking. Roger was the only other man still in work, running a building company with his wife which was struggling in the economic downturn since 2007. His business struggles were a source of profound stress and also impacted on his physical health. Roger's PD also affected how he appeared to other people and how he saw himself as a man, for example as being physically strong, being able to provide and care for his wife and being able to be active in the world. Roger's approach to the interview appeared to portray himself as a jovial, bombastic if slightly aggressive individual, behind which he hid significant worries about his health and about his future. Roger was currently being treated with anti-depressants in order to 'calm' him down. Roger was also experiencing motor fluctuations, could be extremely 'fidgety', potentially to hide tremor and dyskinesia and needed to use two walking sticks to walk anywhere.

Chapter 5. The lived body in PD

Introduction

In the first chapter discussing my findings in this thesis, I examine PD's effects on one of the base poles for our everyday experience of the lifeworld; the lived body (Toombs 1988; Van Manen 1990; Carel 2011). The lived body is the body as we live it, providing our point of view on the world (Toombs 1988; 2002; Pickard & Rogers 2012). We usually experience our bodies in a pre-reflective, habitual manner; 'absent' from our conscious reflection; our bodies are simply 'there' in our everyday experience (Leder 1990; Crossley 2007). However as men's experiences of PD will demonstrate, in PD the lived body is no longer simply there. Instead the movements which characterise our habitual experience of the body, what Turner and Wainwright (2003) describe as 'body ballets' all begin to fall apart. As a result, PD leads to fundamentally altered embodiment, transforming men's experience of the lived body and its place within the lifeworld.

It is this altered embodiment that I seek to explore in this chapter. Rather than my focus being on a biomedical account of PD I am interested in what men faced in their everyday experience, and how the lived body shows up to them through these experiences. To do this I separate the chapter into two parts. In part one I explore men's accounts of one of the central problems they faced in PD, that of movement. In part two I discuss how through problems with movement, the lived body comes to show up for men with PD; disrupting much of their everyday experience of the lifeworld. If PD disrupts the lived body, how does this disruption take place? I then conclude this chapter by discussing some of the wider theoretical implications of the lived body in PD, including the role that social practices play in its experience.

Part 1. The issue of movement; modalities of PD's embodied experience

PD is a highly individual illness, each man experiencing a different constellation of symptoms, a variable prognosis and their own individual medication regimens. However, a number of commonalities also emerged through the men's stories. I describe these through 'modalities of experience'; the dimensions in which the problems men faced grew in their accounts of PD (Van Manen 1998). Crucially these modalities illustrate one central experience influencing all elements of the lifeworld; that of movement. PD has been clinically described as a 'paradigmatic' movement disorder (Poewe 2008). Yet a mechanistic description of PD's effects on the physiological body's ability to move tells us little about the lived reality men's actual experience of movement (Toombs 2002). Through the men's accounts discussed below, movement is shown to be about more than just mobility; it is a fundamental aspect of all our activities; from moving through space, through manipulating objects to the body's most hidden autonomic functions (Seamon 1979). So by disrupting men's ability to move PD disrupts all the domains of bodily activity, thus transforming an essential basis for men's everyday experience of the lifeworld.

In this first part of my chapter I examine how, through changing the body's ability to move, PD transforms this essential element, a key means of attending to the lifeworld. I discuss the problems men faced with movement through four modalities. First I discuss PD's consequences on how men moved their bodies. Second I explore how problems with movement also reshape men perceptions and experience of space (Seamon 1979). Third, men experienced changes to their everyday occupations, providing contexts through which difficulties with movement were understood. Finally, PD transformed the body's ability to communicate with others, limiting men's ability to continue with their routine social interactions (Oberg & Tornstam 1999; Solimeo 2008).

These four modalities; the issues relating to movement most frequently discussed by men, show movement up as a core problem in men's lives, shaping their experience of the lived body and its place within the lifeworld.

The problem of movement.

Movement is a hidden but essential dimension of our everyday embodiment; our experience of the lived body and its place in the lifeworld (Seamon 1979; Toombs 2002). In our everyday projects we rarely need to think about the basic act of moving; of manipulating our bodies in order to achieve momentum. Once learned, we do not ordinarily have to think about how to move our bodies in order to walk, to pick up an object or to complete a task (O' Connor 2007). Instead we can simply move; the lived body possesses a form of motor intentionality in which our bodies simply 'do', smoothly flowing from one activity to the next (Heidegger 1962; Leder 2000; Pickard & Rogers 2012). However as Bob's account illustrates, in PD this habitual, taken for granted experience of movement changes;

> *Bob. I don't know if I can blame Parkinson's for my walking. If it is Parkinson's that's causing my walking, then it has affected me, and it is affecting me more. And balance as well. It's as if I am carrying one tonne shoes. Yeah. It's just, I'm walking, you know, zig zagging, I feel that, and I don't think that that is just old age. So that's what shows up most, that's my walking. It's just that I can't walk very far, and I get so tired, get so tired trying to balance myself, and putting one foot in front of the other.*

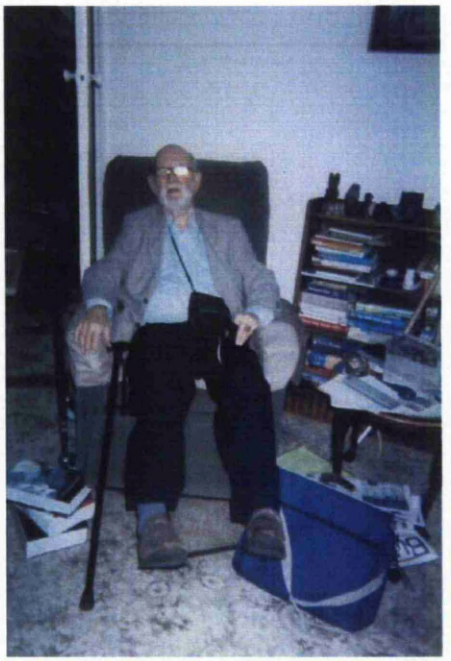
Walking, the most visible expression of movement for the men I interviewed suddenly '*shows up*'. Bob faced problems in multiple dimensions. Bob now struggled with the very act of walking, the autonomic movements necessary to walk; of '*putting one foot in front of the other*'. Walking slowed down. They started to shuffle. It was as if they could no longer lift their legs, making them trip. Walking took effort, far more than it

should. However walking wasn't the only problem men faced with movement. Soon all the body's movements became difficult to achieve, making all their activities increasingly problematic. Peter, Tom, Ian and Harold couldn't raise their arms above shoulder height anymore. Others found they couldn't bend over very far but neither could they stand up straight, forcing them into a permanent stoop; as if they had shrunk. Although men's accounts initially focused on walking, this became one of a whole range of movements that the body struggled to accomplish.

Many men also came to associate PD with slowness. Slowness was a common expression, a feeling located in the body as if it became weighted down; *'there's been a general slowing down of my body, the workings of my body'* (David). Many felt a seeming resistance located within their bodies; as if *'I'm wearing one tonne shoes; 'its like I'm dragging this heavy weight along behind me all the time that's slowing me down'* (Simon). All these experiences could slow them down. But they weren't slow all the time. Perhaps the most widely known of PD's motor symptoms was tremor (Solimeo 2008; Parkinson's UK 2012a);

> *Ian Shaking, shaking, yeah, shaking all over, shaking all over. The tremor in my hands, but the body itself has got tremor. Nervousness, frightened, well not frightened, that's the wrong word, erm, say you've had an accident, or just escaped an accident, you've had a big smash in the car, you know, they're digging you out the rubble and you realise you're still alive and nothing's broken, but you're all shaking*

Tremor was an example of the body moving too much. Tremor gets in the way; it interferes with men's projects.



Photograph 1. Albert in his favourite chair

When Ian's hands shook they literally wouldn't stay still, stopping him from doing many things. But tremor also seemed strange. It not just affected the hand, tremor could be experienced throughout the men's bodies. Ian experienced an internal trembling as if he was frightened, something that could be discomforting. In tremor their bodies seemed to move too quickly, even uncontrollably, doing its own thing; *'the body itself has got tremor'*. In tremor the body moves in a way that wasn't 'them', outside their conscious control.

Tremor also shows up a further difficulty in movement. Movements weren't uniformly slow; the body could, and did fluctuate in its movements. Tremor could come and go; at times it would be barely noticeable, kept under control by medication. But at other times it could be so severe that those experiencing it couldn't do anything. When at its worst Ian could do very little; he couldn't handle things or control things. At the extremes of tremor the body could shake wildly.

Even more so, people could find their bodies switching from being still to moving wildly and uncontrollably. The body didn't just shake. It jerked, even kicking out uncontrollably (known as dyskinesia (Schrag & Quinn 2000)). Although most of the time movements in PD were slow, men could therefore find themselves suddenly moving much quicker; the first of several fluctuating, chaotic and paradoxical experiences that came to characterise the reality of movement in PD (Van Der Bruggen & Widdershoven 2005).

Men's accounts focused the problems PD caused for their intentional movements. But our bodies also routinely move in ways we are barely aware of. One example common to many of the men I spoke to was the small movements we make to achieve comfort when still, all movements which PD made problematic. Albert showed me a photograph of himself in his favourite chair, the only place he could sit in comfort (photograph 1);

> *Albert: This is the only chair in which I'm comfortable. If I sit in any other chair, even with two cushions, my legs ache, my bottom aches, my back aches after twenty minutes. I mean the physiotherapists say every thirty minutes get up and have a walk around for two or three minutes. I'm feeling stiff, that's quite common if you sit for an hour. An hour is too long. Having a meal with guests, I have to stand up half way through, 'excuse me while I explain, I've just got to stand up, have a little walk around', or 'I've just got to stretch', but be careful when stretching, you might find a violent pain.*

Albert recounted a further, seemingly paradoxical problem; he became increasingly still but conversely couldn't stay still for long. The body struggled to relax, to achieve a resting state or to disappear from sensation. In PD the body could become unnaturally still; ceasing to make the unconscious bodily movements our bodies are constantly making to achieve comfort. Instead the body could quickly stiffen up. Albert had to get up every few minutes to walk around, to stretch, to relieve the stiffness building in his

body. This was a common experience; men couldn't simply 'sit' in comfort, they could never totally relax. The habitual movements we are barely aware of making were lost; instead they had to become intentional, driven by changing bodily sensations as the body stiffened up or became painful. The body seemed to demand, to require Albert to move. As a result, all these movements led to a new, paradoxical experience of the body; one where the body struggled but simultaneously needed to move, struggling to find a medium between these two intentional states (Van Der Bruggen & Widdershoven 2005).

In summary movement becomes a core problem in PD, losing much of its everyday, habitual and taken for granted experience. But it is not so simple as simply a growing tremor or men slowing down. Instead movement becomes a series of paradoxical experiences. Movements previously considered 'normal' become difficult, frustrating, even impossible. But conversely 'hidden' movements our bodies just do now had to be brought to attention; they needed to be consciously thought about. And the body could easily and suddenly switch in its ability to move, shifting from a state where it hardly moved at all to one where its movements couldn't be stopped. Through these experiences the body's changing, deteriorating ability to move came to challenge all elements of the lifeworld. For the rest of this section I discuss how these basic problems with movement affected men's lifeworlds, how they affected many of the men's everyday acts and everyday activities; and therefore their ability to habitually inhabit the lived body and the lifeworld.

Moving in space

I first consider an issue occurring repeatedly throughout all the men's' stories; their changing ability to move through lived space. The ability to move opens space up; as a

consequence any illness that limits our movements will mean that space shifts in our perception (Toombs 2002). Albert experienced just this, describing to me some of the difficulties he faced with something as simple as walking around a supermarket;

> *Albert: I (go shopping) usually in small shops, cos going around in a large supermarket like Sainsbury's or Tesco's can have its hazards for PD sufferers. You have to keep stopping, giving way, avoiding trampling elderly folk like yourself, or the youngsters who are scurrying around willy-nilly. I've not fallen over, but the biggest danger to falling over is having a small child or a dog, or an elderly person tottering in front of you. If you have to turn suddenly, you can't do it, and my wife has to turn me over, rather than to turn in the direction you want. You can keep going in a straight line once you're going, but what you cannot do, you can sway to avoid objects, but you cannot make a quick change in direction, or you run the risk of err, injury through falling flat. You have to think ahead, you have to look ahead, are there people, are there small children, dog's, elderly folk, uneven paving stones. Is it better to go on the footpath, or even walking in the road, because at least you've got a bit of bitumen there. It truly is a hazard walking.*

Shopping in a supermarket loses much of its everyday familiarity, instead growing full of emergent hazards having to be negotiated or avoided (Van Manen 1990; Blackman *et al* 2003). Albert, alongside with Harold, Tony, Dafydd and Roger now found themselves unable to make the quick, often instinctive body movements required to dodge, weave and generally negotiate the flow of space. They could no longer slip easily into the flow of crowds, or to comprehend the movements of people around them and respond in kind. New obstacles had to be thought about, their presence considered in relation to their bodies instead of just being dealt with as they occurred; *'you have to look ahead', 'is it better to go on the footpath'*. As a consequence, outdoor space threatened to grow too busy to move within and too confusing to follow, making them feel increasingly out of place, and aware of themselves and their bodies. The body couldn't slip into the everyday flows of movement within public

space, meaning that unless they found ways to change their behaviour, many outdoor spaces grew more and more difficult for them to access (Rowles 2000; Milligan 2005).

Albert also noted a common experience; that space now had to be thought about and dealt with in new ways. For Simon, simply crossing a road had to be thought of differently, becoming a series of demanding tasks now hard to put together;

> *Simon* *when I'm in town I'll stop at the village, in the road, and I'll look, and I'll look, and I'll look again. And I'd thought to myself, this is the green cross code, this is me saying it to a five year old, look left, look right, look left again, look right again, better look left again, just in case, you know. Because you know that when you walk across the road sometimes you don't walk as quickly as you want to, and you can't actually make yourself hurry, so you make sure its safe to cross. Whereas I suppose if I was a typical elderly person, I would just cross slowly and people would have to pull to a halt while I carried on crossing obliviously. Which is a common scenario. Well with me I don't want to be in that position so I'm thinking well how do I overcome the problem, look and look and look, or go to a level crossing. So that's me saying, it's ageing me in that respect.*

The difficulties men faced with simple forms of moving through space; crossing the road or walking from place to place meant space also needed a hitherto unknown level of planning;

> *Harold* *I tend to have to plan where I'm going, rather than walking round, I can't sort of trail around from one shop to another very easily. What I try to do is, find out where the seats are. You tend to find out where the seats are and are not. I notice for example in (town), after being in the hospital last week, I went into (town); I've not been for something like twelve month. Fortunately I knew where the parking spots are and didn't have trouble knowing where to sit. So if I can break my journey, have a rest and then move on that's not so bad. But if you tend to get too far from where you started, I tend to panic, you know, I get a bit worried. And then of course the more I get worried, the more I start shaking.*

Photograph 2. The stairs in Simon's home

Kerbstones, even rough paving all became a threat, something easy for them to trip over, further emphasizing their increasing vulnerability. Distances could also alter to perception. Objects were disconnected from their positions in Euclidian space. Objects in space which were objectively 'near' are now experienced as 'far', sometimes even impossibly far (Toombs 2002). Harold illustrates this experience. Now he couldn't just walk from place to place. Instead he needed to think about where he would park, where he needed to go, where he could rest and the distances between places, feeling anxious, even panicky if he didn't know where he was going. For Tom, even crossing the road outside his home became impossible without aid; he couldn't step off the kerb when walking without help, but nor could he 'bump' his wheelchair up onto the pavement. Men had to think about space in a new, fundamentally different way. All these difficulties were thought of as strange, distancing them from their prior experience of lived space within the lifeworld; as something they moved smoothly, easily through.

Men's experience of the home and its subsequent meanings also changed. Simon and David described some the difficulties they faced around the home (photograph 2);

David *It's the same with the toilet, the toilet seat, trying to get up out of the toilet seat, you've got nothing to push against. So you can be sitting there thinking how the hell am I going to get out of there? (...) The other thing is going to the bathroom. You're desperate to go to the loo to pass water, you can't get your fly open, or you can't close it afterwards because you're stuck. Or if you go on a seat in the toilet, you can't do the opposing motions, like you have to do the clip at the top of your trousers, what do you call them, not the zips. Opposing forces.*

The home also changes in its configuration. Many objects in the home became ill designed given men's new experiences of the movements of their bodies. Home suddenly appeared to be full of new obstacles lying outside men's prior contemplation. Simon, Albert, David, Bob and Tony found that they easily tripped over carpets or froze in doorways. Stairways became a particular threat; an effort to climb up and downright treacherous to climb down (photograph 2). Simon now found the stairs to be a very real danger; so much so he had fitted a gate to stop him falling forwards. The home becomes full of specific problems they now needed to solve; how to eat using cutlery, how to get out of bed, how to use the toilet or how to climb the stairs. As a result the home space changed in many of its everyday meanings, meanings which continued to change as their PD worsened (Mowl *et al* 2000; Milligan 2005).

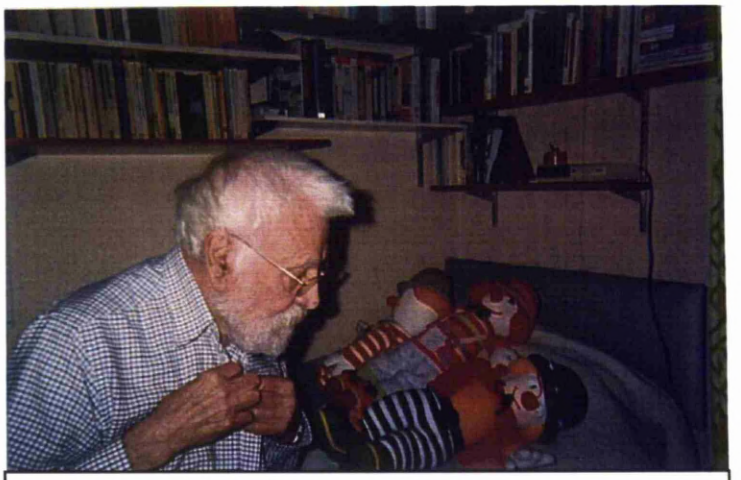
In summary the body changes in its ability to comprehend and move through lived space. The body cannot move through space without thought. Space changes in its everyday meanings, as the body grew increasingly unable to move easily through it. As a result space increasingly becomes a threat to an embodied being-in-the-world, distanced from its prior meanings or those meanings shared with others. (Seamon 1979; Van Manen 1998; Toombs 2002). Above all, in PD space, whether the home or the outside world, takes on an increasingly threatening character.

Movement and occupations; men's activities of daily living

The problems of movement also caused a number of difficulties with men's various occupations. A key theme of men's photographs was to illustrate the various difficulties movement brought to their activities of self-care; dressing, cooking, cleaning, washing (Photograph 3, 4, 5). All these activities grew ever more taxing, frustrating and difficult;

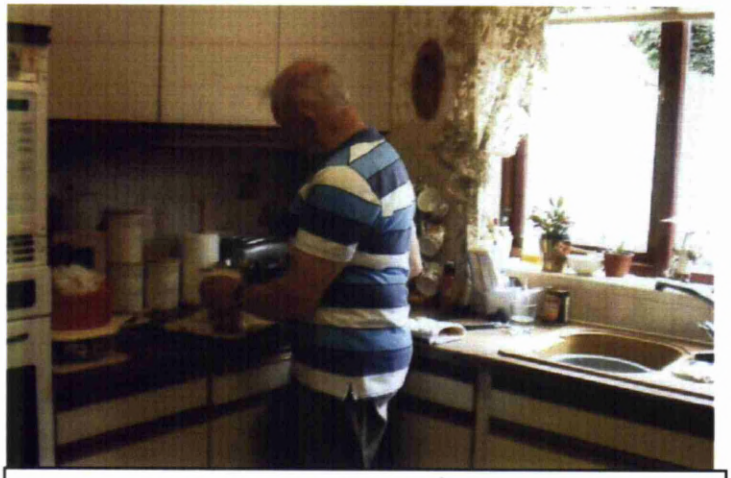
> *Ian Dressing, well I'm wearing these clothes because they're easy to get on and off, but I hate the bloody things. They're anything but smart. It gets harder each day, you know. It doesn't get any easier. And I've got this frozen shoulder which, so I can't get my arm behind my back, and it's difficult getting a coat on. I can only get my arm up to there (to shoulder height). I have to get that one on first, get it up, and then fish round the back with this one, trying to get hold of the other sleeve, get it on. (...) And getting two coats on, there's no chance. (...) Yeah, everything's' a little bit harder, you know.*

Through disrupting men's occupations, the problems of movement affected a wider element of men's lives; their ability to continue with what they considered meaningful activities. Tying a shoe lace, buttoning a shirt or buttering toast became frustrating, time consuming challenges (Photograph 3). Peter couldn't move their arms back far enough to put on a coat (photograph 4). Peter needed help from his wife. Hugh struggled with simple act of cooking, struggling to make a sandwich (Photograph 5).



Photograph 3. Tom struggling to button up a shirt

Photograph 4. Peter being helped to put on a coat



Photograph 5. Hugh making a sandwich

Ian lived alone so instead of being helped to put on clothes, he found himself having to change his style of dress, wearing what he thought were 'scruffy' clothes. He couldn't wear what he wanted, or do what he wanted. Ian's example illustrates a problem faced by several men; that by restricting their movements PD also constrained their agency and choice; forcing their activities, even their life to be organised around their condition rather than their wants, desires or needs. The various movements required for everyday acts were being gradually lost, leaving Ian with a sense that *'everything's a little bit harder'*, challenging a pragmatic masculine embodiment and an embodied, competent self (Watson 2000).

A body losing the dexterity required for mundane tasks also had consequences for men's wider occupations; their hobbies and pastimes, all of which were imbued with much greater personal meaning. A skilled electrician, it now took Bob much longer to do what was previously easy electrical work;

> *Bob Well say I need to change an electric light fitting on the ceiling, I will still persevere and do it. There again with the shaking, I need to get thin wires into little terminals, that can take ten times as long. It's only a half an hour's job, but it can take me two hours, but I'll still try to do it, and I'll do it properly. Cos I don't believe in shoddy work, I never have.*

Home maintenance gave men a means of engaging in leisure activities often associated with masculinity; activities such as DIY or gardening. But given Bob's skills, something as simple as rewiring a light fitting now took *'ten times as long'*. The loss of these abilities were felt much more intensely than activities like washing and dressing; they were too important to give up without a fight (Charmaz 1994). Affecting activities of daily living affected men's basic sense of competence, but affecting hobbies and pastimes affected those activities central to how many of the men defined themselves; a biographical, masculine self, defined through their accomplishments, and activities that should come easily but now often could no longer be achieved (Pickard & Rogers 2012).

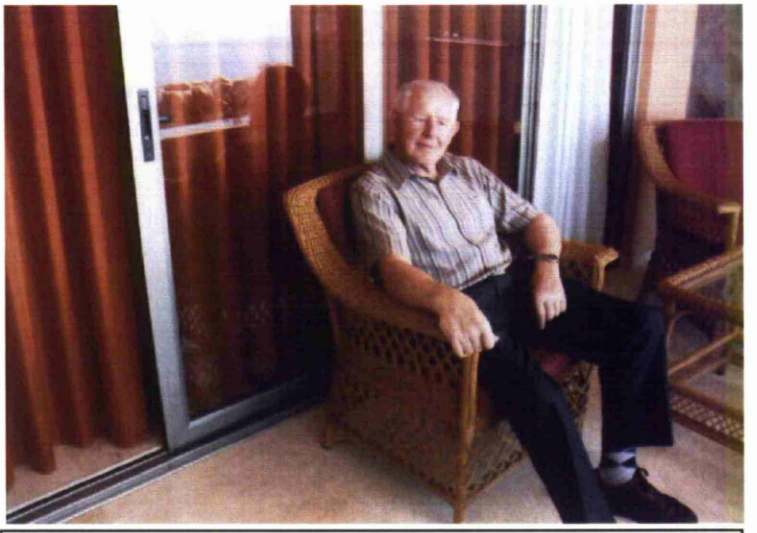
In summary men's occupations were a key domain in which the problems PD brought to movement were experienced. Men's everyday occupations were all embodied; expressed through a skilled knowledge, learned over decades, providing a basis for their bodily acts. PD's symptoms challenged men's ability to accomplish many of these occupations; activities which were all accomplished through the movements of the body, and all crucial to meaning and a masculine sense of self defined by men's acts. To lose these abilities and the unconscious bodily movements they were dependent upon therefore had profound consequences for a masculine sense of competence and a masculine self within the lifeworld, forcing men to engage with a whole range of activities that they now could no longer do.

Movement and communication; PD and the body's ability to interact with others

An important element of the lifeworld is its inter-subjectivity; 'We live in the same lifeworld as persons around us, the world we experience and inhabit is shared by others' (Good 1994 p125). This shared experience is the result of our corporeality; the conscious and unconscious movements necessary to shared forms of communication that our bodies can normally just 'do'. With PD the body comes to struggle with the basic movements necessary for our everyday forms of communication (Miller *et al* 2006). A former lecturer, Dafydd described how speech now became an issue;

> *Dafydd I find I suppose, trouble with my speech. I slur words, I think, I say all the letters, but not necessarily in the right order. That concerns me sometimes. I don't think my speech has been the best for a long time I think. I'm losing the memory, I'm not remembering words right through, and if my speech if you've noticed isn't right through, then I can lose track.*

For a man who relied on his voice for much of his working life, its gradual loss was a profound threat. Simply talking now took effort. Stiffness in the muscles controlling speech meant speech lost clarity and volume, instead becoming mumbling, slurred and quiet. Men struggled to convert thoughts into words and then speak them, often finding that words became stuck 'on the tip of their tongue'. Many found themselves repeatedly being asked to speak up, to repeat themselves or to stop mumbling. Others became monosyllabic, struggling to say more than a few simple words before running out of puff. Men had to attend even to their speech, treating it like shouting, making the effort to project a loud, clear voice. But in everyday conversation this effort couldn't be sustained for long, people would forget to 'force' their voice meaning speech soon grew quiet.



Photograph 6. Hugh in an example of facial masking

Dafydd and Hugh also found that the thoughts accompanying speech also didn't come as quickly or easily;

> *Hugh* *It's embarrassing sometimes, you are in conversation with somebody, and all of a sudden you've forgotten the name completely. It could be somebody well known, who you've worked with, and you just can't. I go through the alphabet sometimes trying to memorise names, remember the next day, it just flew out, all the names. It's unpredictable, if you start a conversation and half way through, 'oh what's he talking about', it's gone from your mind. It happens quite often, especially when you are in company. It's embarrassing that.*

PD threatened to change the nature of everyday social discourse. Declining speech alongside a poor memory meant it was hard to keep up with the ebbs and flows of conversations; to understand others, assimilate their words and then respond. The dynamic interactions of social life moved more quickly than they could either comprehend or take part in, isolating men from its everyday flow. Hugh now needed people to speak to him on his own, slowly, giving him enough time to understand and respond. Sensitivity could help men in communicating to others, but precluded the flowing discourse characteristic of our typical social interactions, once again

threatening to alienate men from the routines of everyday life (Phinney & Chesla 2003).

Speech wasn't the only communicative difficulty men faced. We communicate with others through the expressivity of our bodies; how others can read our moods and emotions through our facial expressions or bodily comportment. However in PD the body and face become increasingly expressionless, growing still, masked, a 'blank' (photograph 6) (Bowers *et al* 2006). All the men I interviewed experienced some degree of what in PD is called 'facial masking', a gradual loss in the faces ability to express what people were feeling (Mott *et al* 2004). A conversation between John and his wife illustrates the difficulties that the body's loss of expressiveness had for day to day social contact;

Wife *it's just the outer appearance that's altered. Sometimes I say to you, don't I? Why are you looking so miserable, and you say well I'm not miserable, it's just the way that the actual physical...*

John *But it affects your face.*

Wife *It affects your facial muscles, doesn't it?*

GG *it does yeah, we call it facial masking.*

Wife *But your own idea of yourself is still the same isn't it.*

John *That's right. That's right, I don't see meself from (wife)'s eyes. I'm good me.*

Even close family could now struggle to know what the men were feeling, believing from their bodily cues that they were grumpy, disinterested, even depressed (Tickle Degnen & Doyle Lyons 2004). Men had to 'force' their emotions, to make themselves smile, laugh or frown, displaying them in an emotional performance distanced from a

typical form of emotional expression and difficult to remember.. In losing the movements essential to embodied forms of communication, the body could no longer act as a pre-reflective surface through which men could interact with others (Miller *et al* 2006). Such an experience could easily isolate men from the wider lifeworld as others now struggled to understand them, leaving them emotionally alone as their bodies ceased to act as an easy site for everyday communication.

Summary

We experience the world through our bodies; our bodies are a locus of experience and locus of intention; a 'body that breathes, perceives and acts, speaks and reasons' (Leder 1990, Toombs 2002). Movement is about far more than mobility, defined through motor functions. Instead it is an essence of our experience of the world. Our ability to move defines us, whether gradual or immediate, its loss has grave implications for an embodied sense of self. In PD the body slows down but could suddenly speed up, its movements growing increasingly erratic and out of control. Its most basic movements, previously hidden to everyday consciousness now had to be attended to, transforming the body's motor intentionality (Leder 1990; Fuchs 2005; Pickard & Rogers 2012). The problems of movement also had much wider implications for the lifeworld. Space changes in its everyday perceptions. Men became disconnected from the everyday flow of social discourse. All the men had to deal with a body changing in its basic ability to move, forcing new patterns of understanding the body and its place in the lifeworld. Movement; defined by medicine as motor dysfunction with PD being a motor disorder, when examined phenomenologically instead becomes an experience with the power to fundamentally disrupt the body, the self and the lifeworld.

The problem of movement clearly makes the body show up in men's experience. Because of its changing ability to move, men had to find new ways to think about, talk about, understand and make sense of the body. In PD, shown in the above accounts, movement makes the body in PD 'show up', to become something men had to think about and manage. Men's experience of movement therefore brings us to a wider concern which I now deal with; how does the body show up in men's accounts of PD? How does it 'dys-appear' and what are the dimensions in which this takes place. I now turn my attention to these questions.

Part 2. Men's changing experience of the lived body in PD

If there is a central tenet to phenomenological approaches to the lived body it is that I do not *'have'* a body, rather I *'am'* my body (Merleau Ponty 1962; Carel 2011). The lived body is simply there; ready to act in the world, flowing smoothly from one activity to the next (Leder 1990; Phinney & Chesla 2003). However, in illness this experience of the lived body changes. The body forces itself into awareness; it ceases to be 'absent' (Leder 1990). Leder calls this experience 'dys-appearance'. Illness makes the body show up to us; it is rendered opaque. We become aware of our bodies and the essential nature of our embodiment as illness makes us struggle to accomplish our everyday tasks. Illness changes how we experience our bodies in relation to others, forcing us to consider how our bodies now look (Solimeo 2008). In this section I consider how the lived body 'dys-appears' in the specific experience of PD. I argue that in PD the body 'dys-appears' through three embodied dimensions; a body now brought into awareness; a body now seen by others and by the self; and a body changing in its felt sensations. Through these three dimensions, PD shows up as a breakdown in the lived body and its place within the lifeworld, a breakdown embodied through men's everyday practices, habits and sensations (Phinney & Chesla 2003).

Photograph 7. Simon on a high ropes course

A former climber, Simon went on a high ropes course as part of a friend's stag celebration. Up in the trees he faced a problem;

> *Simon I mean I've stood on one bit of rope, and the guy said, are you alright, and I said yeah I'm fine. I just can't bloody well make my leg move. My left leg had decided to have a shake. So you can imagine standing on a wire, it's almost like a trapeze, holding onto a rope above your head, standing on a thin rope, and not walking. They thought I was scared. I said I'm not bloody scared; I just can't shift my flipping foot! And my foot was shaking, as if I was trembling. And I was saying, for Christ's sake stand still! And eventually I got my foot to work, and I found by not trying to pick it up I could slide it to the left, so I got it to work. But I was conscious that if I got it off the wire I probably wouldn't be able to put it back on again. And it wasn't fear; it was effects of adrenaline making me shake. But the shaking wasn't helpful to what I was doing, and I couldn't function properly.*

Simon's story brings many changing experiences of the body in PD together into a single account. From a medical perspective Simon gives a fairly typical example of 'freezing'; a motor block in which the body's momentarily ceases its movements (Jankovic 2008). But when examined phenomenologically, this account reveals much more than a simple occurrence of one of PD's many symptoms. Simon faces an

altogether different orientation to the body, a new way of relating to the body experienced through several dimensions. First Simon's leg seemed to want to move of its own accord. It becomes a 'my' operating outside his control; *'my leg decided to have a shake'*. Second in what was a strange, frustrating experience Simon's leg wouldn't obey his instructions; *'I just can't shift my flipping foot'*. Third, his body even seemed to resist him; *'for Christ's sake stand still'*. Fourth, Simon needed to show that this wasn't fear; that *'I'm not bloody scared'*. Fifth, Simon spoke of becoming aware of the effects of deeply hidden, visceral bodily processes; *'the effects of adrenaline making me shake'*. Finally, Simon showed that he could regain control over his body, doing so by sheer force of will; *'I could slide it to the left so I got it to work'*. Simon's account therefore shows up a number of issues about men's changing bodily experience; of having to attend to the body in wholly new ways. The body now shows up to Simon in what was a fundamentally altered embodiment; illustrating a number of dimensions through which men now experienced the lived body.

In this section I seek to unpick these experiences described above by Simon and also experienced by all the other men I interviewed. First I explore how PD brings the body into awareness. The body becomes something men increasingly had to think about and think through, leading to new ways of talking about and therefore experiencing the body. First, I discuss how this transformation in men's sense of their embodiment is seen in the language men used about the body. Most crucially, and a feature of all the men's talk, the body ceases to be a unified whole oriented to the world. Instead now men found their attention being turned inward, on the various parts of the body and their role in accomplishing movement, parts which now struggled to work together;

Ian *the muscles, it's the brain telling the arm to extend and retract, extend and retract, extend and retract, and after about four or five times, it stops. As if it's confused, I'm not getting the message through.*

Parts of the body worked together, but no longer in a smoothly flowing way oriented towards men's projects. The '*messages*' co-ordinating the body's parts in relation to an object or an activity seemed '*broken*', '*confused*', '*not getting the message through*'. Men now needed to think about how parts of the body worked together and how they could be co-ordinated. Rather than activity, the goal of movement had to be movement itself. David talked about getting into bed;

David *Well the first thing you have to do is get into bed, and get into a position where you can use both your legs and your arms. If you turn onto your side, you discover that you've got your weight, your body weight on your arm, and you've got to devise a way of getting your arm from under your body, to free it, so that you can relax, and relieve the pressure on your circulation. So you have foot movements, and I can't explain to you exactly how, but you've got to have one foot firmly on the mattress, and press down, and the other foot tends to lock and you have to wait for it. And then you gradually get that foot down and over the first foot, then you use that for putting your weight on, and at the same time you are pulling your arm, trying to figure out how to describe how you do it, I could demonstrate it better.*

The ways that the body worked together as a whole were revealed in their 'strangeness'. For David it was difficult to explain, even to understand how these movements were now achieved; how the body co-ordinated itself. To get out of bed David now had to think about the body and all its parts; how to co-ordinate his arms, legs and feet; how to distribute his balance and body weight and where to place his body. Given this new form of intentionality, where men had to focus on the specific parts of the body, individual body parts and regions now began to show up. For Simon, for Ian and for David body parts became spoken of as separate entities; '*my arm*', '*that*

foot'. 'the muscles', 'the brain', 'it doesn't let go', 'the alimentary canal'. The body ceases to be spoken of as an '*I*', becoming at best a '*my*', and at worst '*it*', dissociating the self from an increasingly alien body; a body which didn't do what it was told, or that that to be used in whole new ways.

Having to think through the body's acts wasn't limited just to the body's surfaces; how their arms manipulated objects or how their legs walked. A range of previously hidden physiological bodily processes also now had to be thought about and managed. Albert suffered from frequent constipation;

> *Albert Erm, one of the things, believe it or not that involves a lot of energy is getting rid of your faeces. I've had a lot of trouble; you get constipation with Parkinson's. I didn't know that until it happened to me. I presume it's because the muscles that operate the alimentary canal, which is the smooth muscle, is affected. I always thought it was the, you need the excretal muscle to help evacuate when you're going to the loo, the pelvic floor and all the rest. And that's not as good as it should be.*

Body regions hidden deep within the recessive, visceral body largely invisible to everyday sensations also had to be brought into awareness (Leder 1990; Watson 2000; Robertson 2006b). We all experience constipation from time to time, brief periods where we feel the inability to defecate, making us think about the movements of the bowel. But this is usually only passing; our bowels are otherwise invisible to us, working away without our attention. But now Albert spoke of having to manage his bowel in much the same way that he had to manage his arms of legs. Hidden body regions now thrust themselves to prominence, leading to a new, both pragmatic and visceral embodiment in which men now had to concern themselves with their most banal bodily acts; swallowing, eating, 'shitting', 'pissing' even breathing, all of which suddenly have to be brought to the foreground of conscious experience in order to be accomplished.

Even the neurochemistry of the brain now had to be thought about, experienced through their physiological effects on the body and its accomplishments. Simon and Dafydd spoke of having to monitor their excitement. On the ropes course Simon had to monitor his levels of '*adrenaline*' (photograph 7). Too much excitement or its opposite of anxiety could cause their symptoms to suddenly resurface, even making themselves freeze. For Simon, who saw himself as a very adventurous man, this as much as PD's core symptoms stopped him many of his activities, severally curtailing his lifeworld. Therefore even emotions could no longer simply be felt. Instead they also had to be brought into awareness, questioning whether they should do anything that was too 'exciting', or anything that they could be 'too' enthusiastic about. Emotion had to be observed, it had to be questioned and it had to be managed. Men couldn't get too happy or too sad, to do so brought an exacerbation of PD's symptoms, all newly thought of in terms of the visceral neurochemistry of the brain. As the body slows, so the emotional experience of the lifeworld must become flat, empty and increasingly expressionless. All of these experiences required a new means of attending to the body.

In summary all the men I interviewed found themselves experiencing a changing intentionality towards the body. No longer the absent but essential site for men's projects, now the body had to be continually held in awareness, thought about and questioned in almost everything the men did. Could they do this? What would it mean for their illness? What if they froze, or became stuck? What if something was too much fun, or was too exciting? These were just some of the questions filtering into everyday experience. The body has to be attended to as body, rather than simply living it unreflectively (Toombs 1988). Men increasingly engaged with the body's new found awareness through what Toombs (2002) describes as a body-as-object; the body

as an 'it', as a 'my' instead of an 'I'. As the body begins to break down, the body also begins to be broken down, into a series of assemblages no longer working seamlessly together, unable to slip into the rhythms of the lifeworld (Phinney & Chesla 2003; Sunvisson *et al* 2009). Van Der Bruggen & Widdershoven (2005) call this experience the 'well considered body', a body which in PD has to be continually thought about, both on an everyday level and as PD progresses. The act of thinking about the body in this way; as a series of parts, of objects could be and has been interpreted as an apparent reinforcement of Cartesian dualism, dissociating the mind from the body and the body from the self (Sunvisson *et al* 2009). By accounting for the body as alien, men could interpret PD's bodily effects through an unchanging self (Featherstone & Hepworth 1991; Bramley & Eatough 2005; Sunvisson 2006; Sunvisson *et al* 2009). I now consider a further dimension of PD's embodied experience which leads to the body showing up to men; men's new found being-for-the-other.

PD and an embodied being-for-the-other.

Harold described a common experience, occurring here at a supermarket checkout;

> *Harold But I find its difficult, when I go shopping for example, fishing in my pocket for change, getting something out of my wallet, a credit card for example, a real nuisance, erm, putting purchases in a bag, trying to undo those plastic bags. I'm not the only one who has that problem, but I seem to be fumbling and fumbling and fumbling, you know. And I find now it's a bit laughable, I laugh about it afterwards, but at the time I get rather worried about it.*

Harold, along with almost all of the men I interviewed spoke of growing increasingly aware of how their bodies looked to other people. Communication in PD grows harder and harder. Yet this was not the only dimension in which men's their awareness of their bodies in the view of others grew. The changing competencies of the body meant

that routine everyday social interactions became fraught with difficulty. Harold above worried about handling change, opening plastic bags or generally fumbling. It was less of a problem at home, frustrating and limiting but not embarrassing. But if these problems happened in public they had wholly different meanings. Reinforcing the findings of Nijhof (1995), all of these problems could lead to powerful social judgements; that the men were frail, feeble and even incompetent; all experiences which were acutely embarrassing and potentially even shaming.

When men spoke about their growing awareness of their bodies to others they did so through two major themes. First men worried about PD's impacts on their social lives, all evolving from a instrumental masculine embodiment based on forms of 'doing with'. When talking about socialising, all the men told stories about their group activities; sports, games, hobbies or pastimes. David was a keen hill walker, having been a member of a local walking group for many years. Yet now he increasingly worried about holding other people up;

> *David I found it difficult when I was on a walk to go; it took me longer than everybody else to tie my shoelaces. To put my boots on, to reach my feet, and that causes difficulty in putting my boots on, which delayed the walk. Once I had them on I was alright. When we stopped for sandwiches or stuff like that on a mountain, you had a Perspex box, and you would find it very difficult to open the box, and you started having to ask people to open them for you, and that was the time that you start thinking, this thing is catching up on me.*

David's account illustrated a key worry; that they were no longer competent with the various physical activities that their social activities had been built around. David worried about how he must look to his friends, struggling with *'putting my boots on'*, a worry which grew as he struggled to keep up. And as David found himself struggling more and more, he had to consider that his condition would worsen, PD was *'catching up on me'* as he fell more and more behind. Sooner or later he would have to give

walking up, either because he couldn't physically manage or more likely because he felt he held others up. Not wanting to 'hold them up' sooner or later he would have to consider giving walking up, a decision he dreaded, but knew was coming. John found it preferable to stop playing golf than to let his friends see him deteriorate; the enjoyment came from winning and he could no longer compete. Harold continued with his sporting activities, but had to remake their sense of enjoyment focused on the joy of participation, of being–with others rather than of competition, victory and a skilful self (Tulle 2008; Allan & Dixon 2009). PD's worsening symptomology was therefore bound up with powerful social judgements evoked within men's individual social contexts. The accomplishment of a masculine embodiment is always achieved in relation to others. Therefore how men's bodies appeared to others in their acts of doing; the physical activities which men define themselves by will have impacts on a masculine, embodied sense of self. For most, social activities became a difficult and ultimately irresolvable tension between compensating for their abilities, continuing with their social participation while not showing up a body that was too limited and potentially too shameful for public display.

A second dimension was men's wider social presence, the lifeworld we share with the many strangers in the world. The world is full of people we don't know but which influence us in our daily lives; the shopkeeper, the neighbour, the people we pass on our way to work, to school, to the shops. Although we do not know them, our perception of their judgements about us has power; how we feel if we catch a stranger staring at us, or if we find ourselves unable to turn our gaze from others. In perceiving their bodies to be 'abnormal' because of their symptoms, all the men I interviewed found themselves growing concerned about how their bodies looked to others. The most common concern, highlighted in much of the PD literature (e.g. Habermann 1996;

Solimeo 2009) and described here by Hugh, Simon, Roger, Tony and Bob was that others would think they were drunk;

> *Hugh* *Well you feel exposed and, these involuntary movements, they're embarrassing really. People think you're drunk half the time. I mean an alcoholic.*
>
> *GG* *Right, has anybody, have you had any examples or instances of things like that happening?*
>
> *Hugh* *Oh, yeah, walking, some of the time, quite late at night, if you're off balance, 'oh you've had too much have you, put more water in your whisky'.*

Almost all of the men were concerned with the stigmatizing judgements that others could make about them and their bodies. A body moving abnormally because of PD could easily be stigmatised. They could be perceived to be *'drunk'*, *'a stumbling old git'*, even a *'pervert'* according to the display of their symptoms. Although relatively rare, most did have direct experience of these judgements. Most tried to hide their PD, one of the biggest benefits of medications being that they masked their symptoms. But PD's fluctuating nature also had social consequences. Several men worried about other people's judgements even when their PD was under control. Simon worried that others would assume that he was a *'scrounger'*, *'sponging off society'*, undeserving of assistance because during what he called a good day he could function (almost) as well as anyone else, stripping him of an identity as someone legitimately labelled as sick.

In a final dimension, a potentially stigmatising public gaze could have dramatic effects for men's embodiment, experienced through changing physiological and emotional states (Sunvisson *et al* 2009);

> *Roger* *You think they're all looking at you whether they are or not really. In fact you know they are looking at you whether they are or not. That remains quite frightening. I*

mean even more so if you go into an auditorium or mall, shopping mall or something and you freeze, you know, the panic sets in then. It's very hard to break out of that and get the feeling of the legs going again. So I feel as if, that my worlds come down, it's a nicer world, but it's a lot lot smaller.

The potentially stigmatizing gaze of others weren't just 'felt' in terms of their emotional effects; of embarrassment or sham. They had powerful effects on the body, going beyond the blushing, anxiety or awareness of ourselves occurring when we all face embarrassing situations. If men felt a public gaze they often found their symptoms suddenly worsening, exacerbating the difficulties they were facing, as seen in Harold's account of the supermarket. This experience also had emotional effects, leading Harold, Tony, Hugh and Roger to all grow more anxious when they felt a public gaze upon them. Again this worsened their PD, making their symptoms worsen, even causing them to freeze, which then further increased their anxiety, maybe even causing panic, making men flee a scene. Those who were anxious about their bodies therefore faced a vicious circle as public anxieties over their functional abilities in public caused exactly these abilities to decline, causing further anxiety which again worsened their PD. Struggling to find a way to positively negotiate these distressing experiences, Roger, Hugh and Tony found it easier (although not necessarily better) to isolate themselves; to withdraw from a social world hard to cope with; a world Roger found becoming '*a lot, lot smaller*' (Toombs 2002).

In summary, through changes in ability and through its functional appearance the body is increasingly experienced in a form of what phenomenologists refer to as being-for-the-other (Toombs 2002). But this experience takes on a particular character in PD, exacerbating its symptoms as PD's highly visible display made men subject to public judgements about their bodies. PD manifests itself through the visible surfaces of the body; through tremor, dyskinesia, a stooped posture, incontinence and many other

symptoms. In affecting movement the body is seen either to be failing according to core masculine embodied competencies about physical activity, or alternatively were acting counter to social and embodied norms about how masculine bodies should act (Shildrick 1997; Calasanti & King 2007a; Robertson 2007). Under such a gaze the body is once again perceived as an object, now subject to the potentially stigmatising gaze of others, with often powerful embodied effects (Toombs 1988; Nijhof 1995). Given such an experience it is perhaps unsurprising that anxiety is such a common problem in PD (Brown *et al* 2011). The embodied experience of anxiety in PD is a result of the public gaze which has profound consequences for the lifeworld; shrinking it as men found themselves more and more unwilling to subject themselves to this objectified being-for-the-other, instead withdrawing themselves from the public gaze.

Experiencing new sensations within the body

Men's accounts of PD focused on the body's growing awareness as a functional object; a tool declining in its ability to act in the world and an object falling under the gaze of others. But in a final dimension in which the body seemed to show up, these experiences were complicated by changes in the, sensory, 'felt' body (Toombs 2002; Kierans 2005). Most simply men's bodies now felt 'strange', 'unusual' or 'weird';

> *David: Sometimes it can take you two or three minutes to get up, because you're stuck and you can't get your feet to move. It's a strange thing, you're just there, you lock, and you stand there, I could go out in the kitchen now and make a cup of tea, and I could be there with the kettle like this.*

PD was frequently accompanied by strange bodily sensations, many seemingly without a clear cause. Limbs felt heavier. Cramps and pains came and went but without a clear cause. Men's limbs felt a seeming resistance to their actions, resisting as men tried to move their arms and legs. And of course they could be felt to move of their own

accord. In one of the most common effects of PD, men's bodies frequently felt tired, but this feeling was disconnected from levels of physical exertion;

> *Tony* *Its sort of, if I start doing something, if I start mowing the grass or something like that, if its too much for me I start feeling this fatigue business, just drained. Like the tanks empty.*

It was as if the tank had suddenly emptied. Disconnected from wider meanings of illness; feeling ill, sick or in pain, the changing sensations in their bodies didn't seem to make sense. Many of the strange sensations and feelings in the body just 'were', they didn't seem to be a response to any external stimuli. Pain could (usually) be associated with a site of dysfunction, but most of PD's symptoms were not. Tremor could be in the hand, but many of the men knew that there was nothing wrong with the hand, with their stooped back, or with their dyskinetic legs. Rather dysfunction was in a brain that could not be directly felt, but which could not 'get the message through' (Leder 1990). PD therefore led to a number of incoherent, paradoxical experiences located within the recessive, visceral body, a body which didn't work properly, but which did not seem to be the site of dysfunction. Such experiences create a disconnect between bodily sensations and instrumental abilities, shown in men's attempts to make sense of PD (Leder 1990).

Men's accounts of their bodies felt sensations were also closely tied up with medicine and its treatment practices. Most often, they were directly associated with the effects of medications. PD's pharmacological treatment didn't work in the background, bringing the body back to an 'absent' state of health (Leder 1990; Frank 1995). Instead they had immediate and often dramatic effects. Put most simply, men could *feel* their medications working. David described what it felt like when his tablets *'kick in'*;

David *When (medications) kick in, you feel, as if a weight comes off your body, and you feel, ahh, I can move. But it isn't a weight, it's like a restriction, and it frees itself, gradually, and all of a sudden you find you can move your legs much more easily, and you can walk more naturally. It comes on very quickly, but then it dies down slowly after that, so I could be here now, and I could work for about three hours, and then all of a, if I don't take my tablets, if I keep taking my tablet at the right time, it keeps me going.*

Medications could be felt *'coming in'*, a usually pleasant experience described by Hugh as *'returning back to the planet'*. With medication the entire body felt different. The body relaxed; it felt lighter, freer, like a weight had been lifted. Thinking and moving sped up. Medications gave men a *'boost'*; the body felt *'good'*, it felt *'wired'*. But the body didn't return to an absent or habitual state in these experiences. It felt better but symptoms were usually still present; PD continued to make itself felt. Some men, exemplified by Hugh, could also find their medications working too well. A recent dose could also be accompanied by further strange bodily sensations, what Hugh described as feeling *'hyperactive'*;

GG *So you get off periods when (medication's) not working, dyskinesias when it's working too well?*

Hugh *Yes, you're hyperactive then. You just want to do things, and get things and do things that don't really need doing. You see something that's broken down, you want to repair it that minute, you can't leave it till the next day.*

Medications could work 'too' well. The body felt 'too' good, unnaturally so. The body's movements could become dyskinetic, kicking and jerking uncontrollably. Hugh's sensations also changed; he felt himself on edge, driven to do things, even *'hyper'*, in danger of losing control of his actions. In a less common but related experience, Hugh, Roger, Albert and Henry also described feeling new, impulsive desires;

Henry: (consultant) and my wife got their heads together and err, with me present obviously, and my wife's theory was that my Parkinson's was being aggravated by the very fact that I was doing too much. One of the things I was doing was buying and selling cars, which I used to earn a living at, so I've done it for a long time sort of thing. But err, at a time when I should have been retired and relaxing, I was going out and buying two or three cars in a day and putting them on sale and moving them around garages trying to place them. And everything that goes with it and everything that entails with it. And my wife's theory was that I was doing too much, and she mentioned it to (consultant), and he said, 'well why are you doing it if you don't mean to do it'. So I don't know really, I've got to keep going like, and he thinks that its related to the compulsive behaviour that some people get, the gambling, some get it with sex, some get it with shopping or what have you, you know.

Characteristic of what is medically classified as 'impulse control disorder' or 'dopamine dysregulation syndrome' Henry described himself as '*doing too much*' (Wu *et al* 2009). The body could feel almost too good, too driven, men gradually losing control over their actions even without them being aware of it happening. Others had similar experiences. Henry had spent lots of money of new hobbies before rapidly losing interest in them. Tom 'flittered', never getting anything done. More seriously David and Hugh had gambled excessively, while Hugh had also fallen victim to several postal phishing scams. And experiencing a heightened sexual desire, Albert had begun watching pornography for the first time, upsetting his wife. Hugh was aware of his propensity to reply to postal scams but still wanted to reply to them. He now had to manage his desires via '*mind over matter*';

GG Are you still tempted?

Hugh No, well not as much, no.

GG Not as much or not at all?

Hugh *Not as much, still slightly sometimes. I still think, but sometimes you've got to have mind over matter.*

Hugh's family later told me that they now managed his mail and were taking over financial responsibility for Hugh's affairs. Once revealed these men all found themselves having to question their sensations and desires. Beyond giving a reason for their problems, none of the men described receiving any help from medicine to deal with these problems. As a result, in a further example of an altered embodiment and an altered body-self, emotions and desires had to be continually called into question. Were they a normal expression of human wants, or an impulsive desire moving out of control?

Medications could also 'wear off';

GG *How does it feel when the medications wear off?*

David *Oh, hopeless. Well imagine holding a potato, and peeling it, and you haven't got any strength to press the peeler against the potato, you can't do that, you are at the sink. You're like this; I couldn't peel a potato now. Then you're looking for a saucepan and you go (imitates walking) whereas if you are alright you go. Everything slows down. And you sometimes feel your feet are like lead weights, they're there, but they seem to stick to the floor. So you kick yourself.*

Wearing off felt *'hopeless';' it feels terrible to be honest'; 'it's horrible'*. The weight that had lifted now returned. The body once again felt heavy and slow. Strength leaked away, making everything an effort. The body became *'empty', 'still', 'stuck'* or *'drained'*. Most vividly Hugh described feeling *'like a zombie'*;

Hugh. *It just comes on like a light switch. One minute you'll be fine, the next minute you're like a zombie. And my partner notices it straight away. She's only got to look at me, she can tell. Mmm. I'm having an off period. They feel terrible to be honest. (...) When you*

are in an off period you feel so lowsy it's unbelievable, yeah. Your co-ordination, you're like, you are stiff more or less, you can't get going properly. So you just wait for (medication) to kick in and then get back going again

Such bodily experiences couldn't be easily shared, further isolating those suffering from them as they struggled to explain to others just what off periods must be like. During an off period; a motor fluctuation in which the body suddenly slowed as all drug benefit was lost, Hugh's lifeworld body closes down on the body. He feels *'lowsy'*, trapped within a body unable to move. Those experiencing the rapid onset of an off period had little option but to give up what they were doing and simply wait it out. For some they were transitory and rare, but for others, exemplified by Phillip, they were a permanent feature, happening daily and lasting several hours. 'Like clockwork' Phillip entered an off period around 2pm every day. All of his activities had to be fit within an ever shrinking window of opportunity, a dramatic restriction on the organisation of daily life. And sadly, beyond removing him from medication little could be done to lessen their severity; until it wore off several hours later he was figuratively and literally 'stuck' with this often deeply distressing experience.

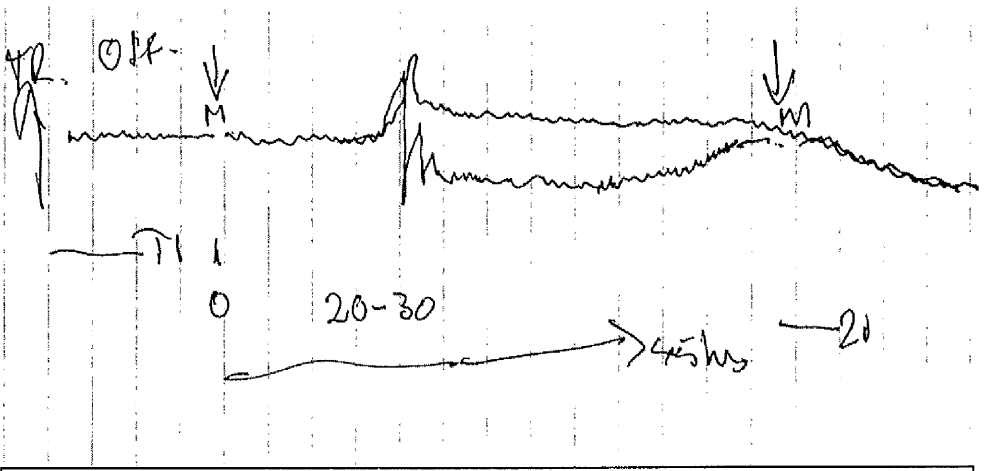


Figure 1. Simon's bodily sensations associated with PD medications. (Medication doses are marked M. Doses led to a peak, followed by decline in functioning until the next dose). (nb Simon's poor, scrawling handwriting is a common problem in PD, associated with rigidity in the fingers)

Finally medications led to a cyclical experience of the body; a fluctuating embodiment happening potentially several times a day. Simon drew me a sketch to show how both his bodily movements and bodily sensations changed, correlating this with his medications (Figure 1). Simon's PD was only mild; those later in the illness experienced much more profound fluctuations in their bodily sensations. This cycle could follow a unique, predictable pattern for each individual. But it could also be inherently unpredictable, changing from day to day, even hour to hour. Medications were either 'kicking in' or 'wearing off', with little time between. Flux becomes a new norm of bodily experience, but one to which men could never become habituated. Even Hugh, who had experienced them for several years still found their onset distressing, unable to simply get used to them; *'they feel terrible to be honest'*. As we can never truly get used to pain, men could never get used to off periods (Bullington 2009). In PD the body is denied what Kierans (2005) calls the 'subtle ordinariness' of an everyday embodiment, an embodiment distanced both from their prior experience and from a lifeworld experienced with others.

In summary, the body shifts into awareness through its changing physical sensations. Men's accounts may focus on an instrumental, pragmatic embodiment; it's declining ability to do its tasks (Watson 2000). But how PD is felt; its changing sensations found deep within the experiential body complicates this account of PD. The lived body in PD is governed by new forms of sensation; sensations which could never be ignored, and which refused to fade into the background. Even if the body was still at that moment it could soon shift in its sensations. When flux becomes the new form of bodily sensation and bodily experience an absent, taken for granted experience of the lifeworld, accomplished through men's acts can no longer be easily achieved. Experiences of the body can no longer be shared as the body fluctuates, making uncertainty a new norm for their everyday experience.

Importantly, these bodily sensations were not simply the result of PD's pathology. Instead many are the result of medicine and its practices. Tremor and rigidity and the sensations accompanying them are part of PD's pathophysiology. But the cyclical experiences of the body; of 'coming in' and 'wearing off'; of dyskinesia, off periods and impulse control disorders are not an intrinsic part of PD. Instead they are side effects of PD's pharmacological treatment. These side effects have profound effects for men's lifeworlds. PD's treatment therefore leads to powerful embodied experiences which although bringing improvements to physical functioning also have the power to transform the lifeworld. The failure of medicine to adequately consider just how severe these experiences can be for well-being can therefore be attributed, at least in part to the failure of medicine to pay adequate attention to PD's lived experience (Stanley-Hermanns & Engbretson 2010).

Conclusion

In this chapter I have sought to explore some of the profound changes PD brings to men's experience of the lived body. In PD the lived body is suddenly experienced as uncanny, something hidden but which now makes an appearance (Zaner 1981; Toombs 1988). The lived body is ordinarily experienced as a unity; both in its body parts and regions and in its place within the lifeworld. But in PD, the unity of the lived body; between the body, the self and the world begins to break down, an experience which accelerates as PD progresses (Bramley & Eatough 2005). The body in PD 'dys-appears'; PD affects the most basic movements necessary for a taken for granted, habitual and everyday existence. Movements become halting, hesitant and slow. The habitual rhythms of the body; its motor intentionality breaks down (Carel 2011; Pickard & Rogers 2012). Movement has to be attended to; considered in its own right rather than to its goals. This new experience of movement was not simply the result of a changing physiology. Rather it was experienced through all the existential dimensions of the lifeworld (Phinney & Chesla 2003; Haahr *et al* 2011). PD's symptoms meant the body could no longer move easily and smoothly through the lifeworld. But this is not its simple, medical description, of a body affected by akinesia. Instead men's experience of the body is also complicated by a number of paradoxical experiences; a body switching between moving too little or too much, or between feeling hyper and feeling like a zombie. Movement, at the heart of the phenomenological experience of the lifeworld, was therefore transformed, becoming a paradoxical experience in PD, between moving too little and moving too much.

When men spoke about the body they do so in particular ways, describing how the body shows up for them. Men's stories about PD most often focused on their changing ability to accomplish a pragmatic and reflexive embodiment; the body's ability to

achieve its tasks and goals in the world (Laz 2003; Robertson *et al* 2010). To achieve this rational, instrumental and as will be discussed in chapter eight, an inherently masculine embodiment, men needed to attend to the body in new ways; as an object, a series of assemblages, men trying to make them work together, even to force them in order to accomplish their goals (Robertson *et al* 2010). Such accounts were a means of positioning the body in relation to the self. But as discussed by Bramley & Eatough (2005) by speaking of a body brought into their awareness they could dissociate the body from the self. Sustaining a rational masculine self, men could talk of a stable unchanging self, imprisoned within an increasingly dysfunctional body (Habermann 1999; Bramley & Eatough 2005). Through telling these stories men could claim that although they had PD, PD was not 'them'.

However the reality of PD's lived experience was far more complicated. Embodiment was an accomplishment, achieved through men's everyday acts, shaped by a number of individual and social ideals, and all of which were made harder by PD (Williams 1996; Pickard & Rogers 2012). The lived body in PD now also felt fundamentally different. Men were forced to feel the body, and therefore to having feelings about the body (Van Der Bruggen & Widdershoven 2005). Even the most basic, often visceral processes deep within the body now had to be 'felt'; affecting men's acts and needing to be observed and managed. It was these changing sensations as much as the functional abilities of the body that forced the body into awareness. Men did not simply experience a rational self, distanced from the body; a reinforcement of Cartesian separations of the body from the mind or body from the biographical self (Pickard & Rogers 2012). Instead the self was deeply embodied, a corporeal experience felt within all the dimensions of men's lifeworlds (Reeve *et al* 2010).

Finally, the lived body in PD is also situated within and experienced through powerful social practices. PD was experienced according to a range of powerful social norms including those determined by socialised expectations about what men should be, and what they could expect from life as they grew older. This study reinforces the earlier findings of Nijhof (1995) who argued that shame results from the breaking of powerful social norms about how bodies should be seen and should act (Nijhof 1995). Medicine and its practices also had profound and largely unavoidable effects on the lived body in PD. Through pharmacological treatments medicine can alleviate many of PD's motor symptoms, at least for a time. However this comes with powerful costs for lived experience. PD's treatment does not return the lived body to either a normative embodiment or an absent experience. Indeed medications come to impose a further form of disruption of the lived body as PD's medications lead to profoundly changing bodily abilities and sensations. Although improving motor functioning according to biomedical definitions of efficacy, from a lived body perspective PD's treatment practices further contributed to a disordered embodiment, one which men must manage continually throughout their day to day experience (Schrag & Quinn 2000; Solimeo 2009).

In conclusion, this study reinforces other studies which have investigated PD's phenomenological experience by showing how it is rooted within a changing lived body (Bramley & Eatough 2005; Sunvisson 2006; Sunvisson *et al* 2009; Solimeo 2009; Haahr *et al* 2010; 2011; Stanley-Hermanns & Engbretson 2010). I also demonstrate that the lived body is experienced not just through its physiological dysfunction or through its individual experience. But neither is it simply a separation of a deteriorating body from an unchanging self; a finding of much of the phenomenological literature on PD. The self is challenged in PD, but this self is embodied; experienced through PD's

consequences for men's pragmatic embodiment; their everyday acts. In addition, PD's physiology is mediated by, indeed is inseparable from medicine and an ageing masculinity; an issue I will to return to in chapter eight. If we are to provide health services which can better address the problems of PD and the needs of sufferers, we must begin by attending to its lived, embodied experience. Such an approach considers the experience of PD as a combination of both changing physiology and social practices, each contributing to what the body in PD 'is' (Calasanti 2010). In particular it critiques a biomedical view of PD as a movement disorder; it indeed is, but this disorder of movement itself touches all elements of the lifeworld. Studies which illustrate the complexities of PD's embodied experience, and the impacts medicine have on the lived body in PD can therefore bridge the gap between the experiential lifeworlds of men with PD and the clinical worlds of medicine, leading to a greater understanding of the suffering felt by men with PD (Sunvisson *et al* 2009).

Chapter 6. PD and Lived Time

Introduction

In this second chapter discussing the findings of my thesis I pay attention to a further problem central to men's experience of PD; that of lived time. In addition to bringing the lived body into relief, illness also has the power to transform our experience of time and temporality (Good 1994; Hyden 1997; Brough 2002; Kierans 2005; Rasmussen & Elverdam 2007). We do not experience time as chronological, objective, 'clock' time; of time as measured via hours, minutes and seconds. Rather we 'live' time, a time that is inconstant but commonsensical, flowing in a taken for granted manner (Ricoeur 1980). It is the time that seems to 'speeds up when we are having fun', or slows down if we are nervous or anxious. As we do not think about the body in our wider practice, we rarely consider time's wider experience; time is an essential structure to the lifeworld but lies in the background of its everyday experience (Merleau Ponty 1962; Schutz 1945; Ricoeur 1990; Brough 2002). But as with the body, in illness our experience of lived time shifts, as we are forced to reassess its flow around us (Toombs 1988; 1998; Brough 2002). As pain forces us to attend to our bodies it can also compress our sense of time; time becomes a series of now's, our only able to focus on the site of pain in its immediate presents (Scarry 1985; Bullington 2009). Our experience of temporality is also linked to narrative; we use stories to tell others of our changing experience, for example telling stories in order to make sense of illness (Kleinman 1988; Good 1994; Hyden 1997). Illness can therefore profoundly reshape the experience of lived time within our inter-subjective lifeworlds (Ricouer 1980; 1990; Van Der Bruggen & Widdershoven 2005).

In this chapter I explore two key elements to men's changing experience of lived time. First I explore PD's effects on men's everyday experience of time; time as experienced through men's day to day acts (Schutz 1945; Ricoeur 1990). PD's symptoms transform the body's position within the everyday flow of time, disrupting men's sense of their place in the world as many of time's taken for granted meanings no longer seem to apply. But new structures, for example PD's cyclical bodily experiences and complex medication regimes rise to take their place, leading men to experience new patterns around which time is organised. A new structure for the everyday experience of time evolves, but one which continues to distance men from the shared experience of lived time (Schutz 1945; Matson 2002). Second, PD transforms men's place within the wider flow of narrative time; an experience of time told through stories, in which our presents are recalled through a biographical past and an anticipated future (Ricoeur 1980; 1990; Tropea 2011). As PD changes, and continues to change as it progresses, the stories men tell about PD also change. These changing stories lead to new meanings, both of a past biography and for the future as sufferers move through the condition. These stories also give men a means to understand the changing roles that various social practices play in their lives, not least the growing role of PD's medical care. I consider these issues through two themes occurring throughout men's accounts; the stories men tell about their condition; how they got it and its past and future effects on their lives, and the stories men told about their medical care. Finally, I conclude this chapter by discussing how men's accounts of PD and its medical care are emplotted; and how a concern with what Mattingly (1998) describes as therapeutic emplotment can lead to more personally attuned care in PD, concerned with the meanings men make for their condition (Tropea 2011).

Part 1. The changing experience of everyday time in PD

First I articulate the changing experience of everyday time in PD. Early in his interview, Henry described what had now become a fairly typical morning routine;

> *Henry Tuesday, difficult to get up to start with, difficult to get out of the room, severe pain in the hips, the hip I should say. And err stomach aches, and the Chinese shuffle. So I get up and I make my wife cups of coffee in the morning, I get up, six o clock at the very latest, very latest, I'm usually up at five o clock to (take a tablet). Make her a cup of coffee, two or three cups of coffee. I'll have my breakfast about eight o clock, half past eight, eight o clock's the tablets and half past eight breakfast. And then if I'm still feeling that way I'll go back to bed for about an hour, get up and quite often its improved over that hour, which is probably as I've said before the medication kicking in,. Erm, after that its just a case of doing things a bit slower for the day, you know.*

Henry's account provides a snapshot of the challenges PD brings to the routine organisation of everyday life. Henry wakes very early in the morning, because of pain, but also because he needs to take the first of 20 tablets, taken each and every day for his PD. He then stays in bed for up to an hour, waiting for his medication to 'kick in'. Even after kicking in, waking up, getting washed, dressed and having breakfast all took much longer; it could take Henry several hours to be truly ready for the day. The point of this account is to show just how slow and how regimented Henry's life had now become; *'its just a case of doing things a bit slower for the day'*. Henry's experience was far from unique; but serves to illustrate the significant changes occurring in the routine organisation of men's lives.

First I describe the central feature of Henry's account above; the disruption to everyday time brought about by PD. The experience of lived time is intertwined with the lived body; time being experienced through the body's day to day acts. Therefore, as the body slowed in its movements, this 'slowing' has significant effects for the

experience of lived time. Harold described to me his sense of how he and his body was slowing;

> *Harold. I think the thing I find most obvious is I'm much slower in doing most tasks. I find the biggest difficulty, certainly being on my feet, walking, and more so possibly, standing still. Erm, not that I get out of breath particularly it seems to be physically hard work to walk. I'm never in any pain at all, it doesn't hurt in that sense, but certainly that's been the overriding thing I think, is being slow.*

Akinesia is one of PD's cardinal physiological symptoms (Jankovic 2008). Yet slowing had far greater impacts than just slowing the pace of physical movement. Instead it transformed men's place in the world. But going beyond the physical body, the 'mind' also seemed to slow. Simon found concentration more difficult;

> *Simon Lately I have this problem which err, I troubled the doctor with, is (inaudible) where I close my eyes when I'm thinking. I'm doing it now. Erm, it's a way of concentrating the area of the brain that I want to do the thinking with. Cutting out unnecessary input. It causes a problem sometimes but erm, most of the time it's just a nuisance, but it reminds me that it's there, you know*

In a strange experience, Simon had to 'close his eyes' to concentrate; as if blocking out any external stimuli that could affect his clarity of thought. Only one thin could be thought about or done at any one time. Simon illustrated what was a common issue, that the process of converting emotions into thoughts then converting thoughts into action became stilted and disjointed, ultimately slowing them down. As concentration slowed it caused other difficulties;

> *Tom Erm, well what I'm trying to do, and sometimes I'll go on, I'm doing a, we did a Lands End to John o Groat's (cycle ride), and I wrote a little manuscript from it, but now we have this ability to put photographs in it, so I was doing, putting photographs in, but I started that off, but it's in the back brain because I flitter. I change my mind every five*

minutes. My grandson is eighteen next year, so I thought I've got some of his great great grandfather's books, so I thought I could take one of these books, and take some of the photographs of his grandparents in. It'll be some sort of gift for his eighteenth. So I thought I'd do that, but I couldn't get that off the deck.

Tom described what was a common experience, what he called '*flittering*'. He couldn't settle on any one thing, few things could hold his attention for long. Tom found himself always moving from one job to another, unable to stick with any one thing and never getting anything done. Simon, Hugh, Henry and Albert had similar problems, finding themselves driven to start new tasks, new pastimes, even routine activities, all of which quickly faded from their attention. The effort and attention needed to finish things couldn't be found; they grew too tired or lost interest, their attention quickly wandering. All this had impacts for men's activities. Ian couldn't get his house properly cleaned; it was full of boxes, bags and clutter he couldn't remove; it took too much physical and mental effort. Life filled with a variety of unfinished projects they simply couldn't get done. As PD progressed the lifeworld became too busy, full of things they had been forced to give up, all threatening to overwhelm them.

This experience of 'flittering' could also challenge what several men thought of as a productive, masculine sense of self. Running a building firm, Roger was used to '*multi-tasking*';

Roger Concentration is going quite a bit now. (...) Yeah ten years ago I could balance three or four balls up in the air, blindfolded and standing on one leg. I used to deal with things in my own little way. If I had problems I could file it in its own pigeonhole, I'd say I'll deal with that today, I'm not going to go ape-shit about the other four because I can't do anything, but I control that one today, and deal with the other ones tomorrow. And that's quite a good way, because everyone else would run around like a headless chicken you know, but as long as the head keeps a steady hand on the ship I was able to do alright. Now I'm down to struggling to balance the one ball.

Photograph 8. Bob's garden. It now took several days to trim his hedges and mow the lawn

The 'balls' we all routinely 'balance' in our everyday lives could no longer be managed, differentiating Roger from a prior self. Instead PD forced Roger and others to live life at a much slower pace, doing one thing at a time, always mindful of having too much going on (Munro & Belova 2008). As a consequence the routine sense of dynamism, the activity, productivity and busy-ness that was a common feature of Roger and other men's lives was eroded (Hoglund *et al* 2009).

The slowing of the body and of life in PD again led to a number of paradoxical experiences. First, as life slowed, it strangely seemed to become more and more busy;

> *GG* *And what does (taking the tablets) mean for how you organise your life?*
>
> *Tony* *Well it means you have to fit things into a smaller space, you know. You have to sort of say I've got to go shopping, I've got to go to (local town) I, usually takes me about an hour and a half, err, how do I feel, twitchy, shaky, no, not so bad. Okay, take your eleven o clock one, get in the car and go. (laughs). like if I have to take the car in for its MOT or something I've got to be in the village by sort of half eight, so I've got to get meself up and shifted. Erm, and that's a bit of a nuisance, because it takes me sort of, an hour to wake up really. I'm probably into the village, drop the car off and I'm back home before I've woke up. Erm, but yeah, other than that, its, it's a nuisance but there's nothing I can do about it really so, you just learn to live with it.*

Photograph 9. Harold's garden. Harold now had to pay handymen to do the physical task in his garden

Tony had to *'fit things into a smaller space'*. When activities of daily living took so long and took so much effort, less, and often little time and energy was left for the hobbies, sports or other activities that gave life meaning. Instead activities had to be thought about in terms of whole new timescales, new forms of effort having to be applied. Bob was a keen gardener but now found trimming the garden hedge (photograph 8) could take days, even weeks, leaving Bob exhausted for several days. Activities grew more and more fragmented; ten minutes then a rest, ten minutes then another rest. Everything stretched, taking much longer, meaning that nothing ever seemed to get done. Given such experiences, even routine tasks could easily overwhelm them. Unsurprisingly, it could be hard to find either the energy or time for such things. Harold now paid a handyman to look after his garden (photograph 9). Hiring help was useful, but forced him to acknowledge all the gardening tasks he could no longer do; mowing, trimming, planting, digging. Bob and Harold illustrate how once again men's sense of

time was expressed through acts of doing. For Bob, talking about the garden showed how he managed these problems, but for Harold, gardening only reinforced what he now struggled to do, what he was losing. Unsurprisingly then, the slowness and change in both activities and expectations could disrupt men's acts, and therefore threaten an autonomous, active and productive masculine self. In requiring so much effort PD meant all these tasks took too much effort and far too much time; forcing both a slowness, but also paradoxically a fullness on everyday life that men could no longer keep up with.

In a second paradoxical experience, several found that they couldn't change the speed at which they moved. Simon gave me an example of what happened if he hurried;

> *Simon* *it's a kind of thing that causes adrenaline levels to raise anyway, butterflies, excitement, and enjoyment raises your adrenaline and anything that raises adrenaline causes the stiffness to increase, quite dramatically in my case. You can see it; it hit me bolt, like lightning. (...) So adrenaline is a, has a negative effect on me generally. Overcoming that to actually have fun on this (high ropes course) was quite an achievement*

Life could no longer be hurried; it couldn't be lived at different speeds. If the men tried to do anything exciting, or do anything quickly PD again made itself felt, causing the body to slow or even freeze. But the body could also suddenly speed up. In an example noted by Solimeo (2009) and also noted by the men I interviewed several had bruises or scrapes, telling me stories about how they had literally walked into walls, the effects of Festination (shuffling steps) and propulsion a sudden forward acceleration) making this a surprisingly frequent occurrence. Men's tasks had to be weighed up against their bodily consequences; anything exciting meant the body could freeze or could suddenly speed up, while anything effortful could take days to recover from. PD now forced life to be lived at the pace of the body. Slowness had to become an

intentional act; men forcing themselves to slow their bodies down physically, mentally and emotionally. No longer an 'absent' experience of the body in time, life had to be lived at one of two speeds; either frustratingly slow or at a stop (Leder 1990; Van Der Bruggen & Widdershoven 2005).

The experiences described above all had consequences for men's position within a shared lifeworld. Simon, now unable to work found the routine organisation of the day was losing many of its everyday meanings;

> *Simon Then you get the situation where weekends don't mean anything. So you know one day is as good as the next. You don't bother with the calendar, you don't think about dates. That means you forget dates and people wonder why you've forgotten their birthday, because suddenly the calendar doesn't really mean anything. Whereas people who are in regular work and employment, they see their week differently. Friday and Monday aren't different to me, whereas they were before. Friday was the end of the week, a bit of a break, Monday was that Monday morning feeling. I don't get a Monday morning feeling, but I don't get a Friday afternoon feeling either. So you have to artificially make it.*
>
> *GG. Do you miss that?*
>
> *Simon. Yeah, yeah I do in some ways. I miss the erm, ordered sense of it, and the fact that I don't see days as important, people don't understand why I don't see days as important. So I miss being different in that respect, I don't like being different. I mean, you know, one likes to be part of the crowd. Yeah, I certainly miss being involved in things with people on an everyday basis.*

Habitual meanings of time were no longer shared; typical meanings of time; of weekdays and weekends or holidays ceased to apply to Simon's life. When '*one day is as good as the next'*, life loses much of its order, routine and purpose, taken for granted previously in Simon's life. Slowing forced new ways of experiencing the day, dominated by the mundane with little time for meaningful activities. Such experiences

could also the men from those around them; as Simon noted *'people don't understand why I don't see the days as important'*. In disconnecting the men from the day to day structures of lived time, time lost many of its everyday meanings. But these were replaced by new meanings, structures and routines; each bringing new ways of organising time and all organised around PD. I now consider some of these new structures.

Experiencing new patterns for the organisation of everyday time

PD meant that for many of the men, the routine organisation of their days now transformed, as Ian described in terms of cooking;

> *Ian cooking, I mean, if I'm medicated up, and reduced the tremor to a small amount, I can cook quite well, but if I've gone past my medication time, and I need to have food before I take my medication, then it's not got to be cooked food because I couldn't cook it. Trying to get things out of a pan with a ladle or a spoon and I just can't do it. And err, a fish slice (2) I just can't get a sausage out or anything like that, you know. Made a bacon sandwich the other day and I burnt my fingers trying, in the end I gave up, trying to get the bacon on the knife to lift it out of the pan, and burnt my fingers doing it.*

Time changed in its everyday structure. Many activities couldn't be carried out at their 'normal' times. Ian illustrates this experience in terms of mealtimes; he could only cook food when he was 'medicated up'. Mealtimes, washing, cleaning, housework or gardening increasingly could only be done at certain times, when they weren't too tired if they had enough time in the day or if their symptoms allowed it. Activities were increasingly governed either by men's medications or by their changing bodies. More and more life had to be organised around PD, further disconnecting the men from the wider flow of lived time.

Ian's account of having to eat according to when his medications and symptoms allowed, rather than when he was hungry revealed a new pattern for the organisation of everyday life, one determined by his body and its fluctuating abilities. To control the body a new routine for the organisation of everyday life emerges, shaped by medicine and its practices. Calendars and diaries were full of hospital or clinic appointments, of physiotherapy classes, of day centres and support groups. Visits to PD consultants were typically every three to six months, but for many could be much more frequent. Indeed Albert found himself attending one clinic or another almost every week, for PD or for his other illnesses. Physiotherapy or speech and language therapy may need the men to do daily exercises. Yet it was medications that had greatest impact on the routine structure of the day. Henry described his daily medication regimen to me;

> *Henry I've got my tablets, my time alarm all in one go. Now what I've done with that Stalevo (a stronger version of levodopa with an added drug to slow its absorption into the brain), is 6 o clock, 2 o clock, 6 o clock, as is mirapexin, so I take two tablets out of that box, 6(am), 2(pm) and 6(pm). And that one is Stalevo with Azilect (An adjunct medication to lessen side effects), and that's once a day, so that one again is once only in that combination. Now the Madopar ('standard' levodopa) is three times a day, 8(am), 12(pm) and 4(pm). And then that one there is at 10 o clock, and that's the last Stalevo of the day.*

What might initially seem excessive became a fairly typical medication regimen. But it meant Henry could take anything up to twenty tablets a day just for his PD; the first at 6am, the last at 10pm, with rarely more than two hours in-between. Life had to be ordered around these times. Men dealt with the demands of taking the correct dose at the correct time in different ways. Roger relied on his wife to tell them to take his tablets. Henry used the alarm settings on his mobile phone. Several received their tablets in pre-organised blister packs, delivered to them by their pharmacists. Albert

kept all his tablets mixed up in a bowl by his chair, taking them *'like smarties'* as he needed. Phillip even wore a pill box full of tablets on a pendant round his neck. My interviews were frequently punctuated by the beep of medication alarms or by reminders from wives. Others had boxes of medications scattered throughout the house, or a cupboard dedicated to their tablets. Several men had been on these regimens for years, even a decade. But it was never as simple as just 'getting used' to their patterns. The demands of taking medication grew as the disease worsened, men taking more and more tablets more and more frequently. And the demands of medication reinforced PD's ever present nature; that it was *'there all the time'.*

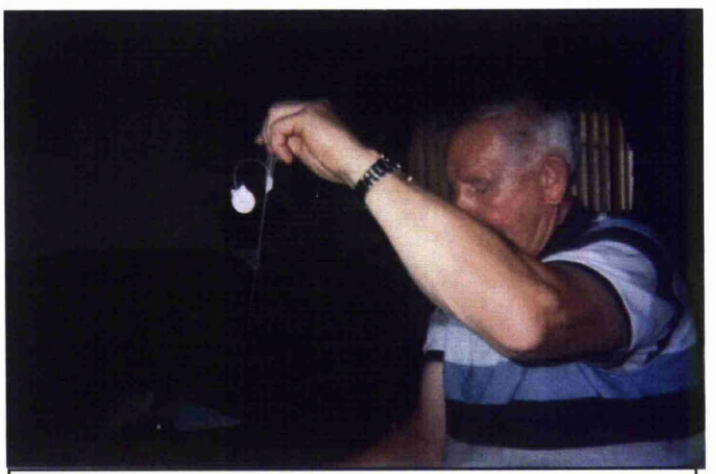
In early disease Simon resisted taking his tablets, a small act of rebellion giving him some sense of control over the demands of medications;

> *Simon; So Parkinson's is there all the time in the background. That's the main thing. Then really there's the medicine regime, keeping control of that, the tedium of it. You get days when you think I don't really want to take these bleeping tablets. And you don't take them. There are days when I'm able to preoccupy my mind with something of interest, and I don't need the tablets.*

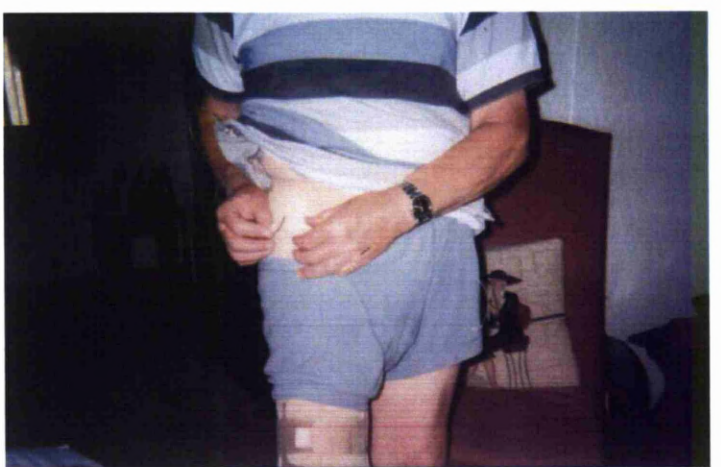
Although Simon took six tablets a day, far fewer than Henry, he still disliked taking the few he now needed and the control they had over him. But men's orientation to medications had to change. As PD worsened most of the men quickly learned they *had* to take their tablets, taking the correct dose at the correct time became essential to men's continued daily functioning;

> *Hugh Well it was just getting the medication more, correct isn't it. It's very important getting the timing right, if you miss an hour or, it takes a long time to get it back on form again.*

Photograph 10 Hugh preparing a syringe



Photograph 11. Hugh preparing the IV line



Photograph 12 Hugh injecting the line into his waist

All the time, time had to be considered. Medications couldn't be missed. Such regimes could be extremely demanding; tedious, requiring men to constantly 'watch the clock', aware of when their next tablet was due. And where they would be when they took it. Some medications also required more than just taking tablets.

The everyday demands of medications were exemplified in Hugh's experience of apomorphine, a medication used to control motor fluctuations. Hugh took several photographs to show just what taking apomorphine entailed (Photograph 10-12). Much of Hugh's life had to be organised around the apomorphine pump. Preparing it was a surprisingly technical process requiring a new form of experiential knowledge how to prepare his medication and where to inject the pump; Hugh quickly learned that if he injected the IV line incorrectly he could experience painful abscesses. And the pump created new temporal demands. There was usually only short period every day when the pump wasn't operating, during which Hugh had to get washed. He had to at home at the same time each day to refill the pump. A district nurse could have administered apomorphine but Hugh preferred to do it himself; having to be at home at the same time every day for a nurse visit was too constricting. But all these difficulties were worth it for the benefit; taking apomorphine was better than experiencing the full effects of uncontrolled off periods. Hugh's account of apomorphine illustrates many of the lived dilemmas of PD's pharmacological treatment; a balancing act between the declining benefits and growing demands of treatment, each driving a re-organisation of everyday life.

Why did the men feel they had to pay such attention to their medications? All those I interviewed had experienced the consequences of missing doses; the potentially sudden, rapid and severe return of their symptoms;

Tony *like yesterday, I realised I missed a tablet and I couldn't go anywhere, I mean I have sort of, very tired days where I've run out of steam, and I think, oh no, you're not going to be able to, and you know, I had to sort of zoom to the shops in (local town), and then think, but I want to, then find a toilet somewhere and come home again, it just ruins your life.*

If a dose was missed or if medications wore off symptoms could return in minutes. PD could 'creep' up on them, forcing them to drop whatever they were doing and retreat home. Only by strictly adhering to their medication regimes, by holding time constantly in awareness could wearing off be avoided or lessened. Roger spoke of the consequences of missing a dose;

Roger *Like if I'm in my little study down there, and I'm working on something that interests me, I forget you see, and you've okay if you forget for half an hour, maybe an hour sometimes, you go alright then bang, shit why didn't I take that pill, and its, then you're sat there, you take your pill then wait. And that's so frustrating yeah that's a good point that. Frustration of, because you didn't take your tablet you have to sit and wait and for me every day is precious.*

Medications came to occupy an immediacy in the men's current experience; they couldn't forget about them and they couldn't fail to take them. They couldn't become too invested in activity; if they did it would be easy to forget a dose, leading to a sudden return of symptoms and their potentially getting 'stuck'. Medications could be managed, but they always had to be thought about; they couldn't just become a taken for granted, habitual part of the lifeworld. In sum, medicine, and more specifically medications came to provide a whole new visible structures for the experience of everyday time; a life now organised around the beeping of a medication alarm.

Summary

As PD disrupts the lived body, PD also breaks the habitual, routine organisation of lived time. To conclude this section I draw on what Schutz (1945; 1971) describes as a 'common time perspective' (Good 1994);

> "In and by our social life with the natural attitude they are apprehended as integrated into one single supposedly homogeneous dimension of time which embraces not only all the individual time perspectives of each of us during his wide-awake life but which is common to all of us" (Schutz 1945 p541)

Schutz' common time perspective gives us a means to reflect upon our habitual, taken for granted understandings of everyday time, a universal and historical perspective, shared between us, but occurring so deeply that we are rarely aware of it (Schutz 1945; Good 1994; Brough 2002). However, the various experiences described above all disrupt a common time perspective. Its everyday, intersubjective meanings could easily be lost in PD; a routine sense of time could no longer be taken for granted, and could no longer be shared. Importantly the body, a body struggling to accomplish its acts was the point of origin for this break with a common time perspective (Van Manen 1997; Haahr *et al* 2011). In PD the experience of lived time could not be divorced from men's experience of the lived body (Munro & Belova 2008). As a consequence, the lifeworld began to lose many of its everyday meanings.

As the everyday structures of time in the lifeworld were eroded, new patterns of organisation rose to take their place. A variety of patterns emerged; of activities of daily living taking so long that they now dominated much of everyday life. But clearest as a new temporal structure was medicine and its practices. Across many of these new

patterns was a common experience; that time had to be constantly held in awareness; an object attended to throughout men's everyday acts. Instead of the mundane flow of everyday time life became increasingly structured by clock time, by a medical conception of time; when to take their medications and how long they would last (Schutz 1945). As the body had to be brought into relief, so did 'clock' time. And because of PD's progressive nature, the demands of medications were permanent, indeed they only increased. In later PD everyday time becomes dominated by the cyclical patterns of symptoms and medications, much of life being organised around these new, alien patterns. Although beneficial and better than the alternative of an untreated PD, medicine and medications could therefore reinforce an alienation from an intersubjective lifeworld. Men's experience of everyday time was irrevocably changed, disconnecting men from its everyday flows and reinforcing just how different their lives had become; a fundamental disruption to the lifeworld.

Part 2. Narrative and the experience of lived time.

In this second section I discuss men's experience of biographical or narrative time; a present defined by a recollected past and an anticipated future (Ricoeur 1990; Mattingly 1994; Mishler 1999). Ricoeur (1980; 1990) and Bruner (1987) argue that we make meaning from our experiences through narrative; the creative telling of stories about our lives (Brough 2002; Randall 2007; Munro & Belova 2008). Lived time is also narrative time; made sense of through the telling of stories; drawing on past, present and future through a three-fold rather than linear experience (Ricoeur 1980; Kierans 2005). By paying attention to these experiences, I hope to learn much about both how PD's experience changes over time, how people experience PD at these different stages of the illness, and finally, the role that medicine plays in shaping this changing temporal experience (Atkinson 2006). The care men received was critical to a wider

story, in which men looked towards the future, trying to make sense of what PD would mean for them (Becker & Kaufman 1999).

I am concerned with the stories men told about two areas key to PD's lived experience. These stories formed a central means of making sense of a changing experience of narrative time, and which revealed the complex nature of men's interactions with medicine and its practices. First I examine the stories men told about the care they received and crucially its role in men's attempts to make sense of their illness (Hyden 1997). Starting with the diagnosis, men told stories of a body changing over time; earlier in life and in their current experience. Crucially, the provision of medical care shaped how these stories were told, making powerful contributions to men's subsequent meanings. My second set of stories concern the journey men took through the disease. How these stories were told revealed much about the changing nature of PD's experience over time, including how men thought about its future effects.

Men's changing stories of PD over time

A central part of the stories men told about PD was how they changed over time; developing as people moved through the illness. As they moved through PD men engaged with medical practices and medical narratives, telling different stories at different stages of the illness. Through these changing stories, men derived their own understandings of their illness based on PD's effects at that time and also based on how these effects had changed (Mattingly *et al* 2011; Twigg *et al* 2011). I focus on two particular elements of these accounts. First I examine how men's stories of diagnosis emerged and their subsequent impacts on the stories men told. I then use a case study of Roger's changing story of his medical care to explore how men's experiences of PD and their subsequent meanings could evolve and change.

I start with the point at which the majority of men's stories of living with PD began; the diagnosis. Although men told differing stories of diagnosis, a number of similar themes evolved. First, and evocatively described by Roger, diagnosis was the point where everything changed;

> *Roger. Erm, the most memorable thing I think for me is err, when I was told I had Parkinson's by the then consultant, who was visiting (home town) once a week and before going to his clinic I didn't have any idea what he was going to say. In fact I thought I had a trapped nerve, because I reached round to the back of my car for my briefcase and I thought I'd pulled something. And to be told within, probably less than five minutes that you've got Parkinson's disease, there's no cure for it, it felt like being written off, out of the human race really. And then going home and telling my parents, my own family, I think it's true to say I, I felt like going away into a corner and crying, but you couldn't because you had to keep their spirits up. Thereafter you sort of come to terms with it. You have to.*

Even 15 years after diagnosis the emotive power of Roger's account is palpable; '*it felt like being written off, out of the human race'*. A minor ailment becomes world changing. The future comes crashing down, life as Roger knew it was over. For Roger a successful masculine self was disrupted, but also forces him to respond to PD in particular ways; '*you sort of come to terms with it. You have to'*. Roger's story of diagnosis is an exemplar of what Bury (1982) calls biographical disruption; a discrete, immediate event, and a break with a biographical identity associated with a lost former life (Charmaz 1994; Williams 2000; Solimeo 2009; Reeve *et al* 2010).

David had a similar experience of diagnosis, but also described to me how he came to seek help;

> *David It was strange really how I was diagnosed because I was told that Parkinson's was a very difficult disease to diagnose. I was walking down the road here when a lady doctor from across the road, who I'm friendly with, being in the neighbourhood, came over*

and said could she have a word with me one. And I said yes, come along, and she said, I think you have something seriously wrong with you. I said what do you mean, well I, something deep in the back of my mind tells me that there's something seriously wrong with you and I'd like you, you should go and have it checked. So I said well what is it? She said well I hesitate to say but erm, you can curse me, you cannot speak to me ever again, but I feel it's my duty to tell you, and what she told me was that she suspected that I had Parkinson's Disease.

In a frequent experience the point at which David sought a diagnosis was triggered by others, who on spotting their PD told them to seek help. For Bob it was his son. For David it was a neighbour who happened to be a GP. Men's stories show further focus on a body being suddenly forced into their awareness, revealed through their 'being-for-the-other'. How their bodies looked to others around them forced David and Bob to recognise the newly problematic nature of their health, transforming their bodies from well to potentially ill (Solimeo 2008; Carel 2011). Importantly, telling such stories also allowed those individual's telling such stories to continue with an archetypal, normative story of diagnosis; as an inherently disruptive event awakening men to their new circumstances (Bury 1982; Charmaz 1994; Faircloth *et al* 2004a).

But as men learned more about PD, these stories of PD as a sudden illness grew more difficult to sustain. The nature of PD meant they hadn't suddenly fallen ill. Several recalled that it took many consultations, and frequently even several years to gain a diagnosis, a period of uncertainty where men were unsure of what was going on. As men began to build a knowledge about PD several grew to recognise that they had actually been 'ill' for months, perhaps even years beforehand, even if their bodies showed few signs. As men realised this, their stories searched through their earlier biographies for any signs of their PD. , David began to recall some of the earlier difficulties he faced when walking in the mountains;

David; I had noticed that there were times where I had to be very careful on the mountains. Especially when walking along broad ledges, or on the crest of a mountain, on in stony places, because I would catch the top of a stone, with the grip of my feet, my soles, and if I wasn't careful I would go hurtling forward. And so whenever I came to a place of danger, I always used to take extra care. And I had thought myself about going to see the doctor about it, and erm I noticed it was the same foot every time that I caught, it was this right foot. So err, left that part of the, of course now coming down to (consultant) and his confirmation of Parkinson's Disease,

Earlier signs of problems were brought into awareness. New recognition of such experiences led men to ask wider questions, namely when had their PD truly begin and perhaps most importantly, why did they have it. John spoke about events in his earlier life, possible precursors to his illness;

John It first manifested itself in about 15 years ago, in my mind, when I started to have trouble breathing, and shortage of breath. I went, and I was in the doctor, I went to see a specialist, with regard to my breathing, and he said there was nothing wrong with my chest. And I went on a regular basis, for seven or eight years, and they couldn't find anything wrong with me.

Strange experiences earlier in life were re-interpreted as men remade their biographical histories in order to incorporate PD into their lives. Vague problems; aches or brief episodes of stiffness dating back many years suddenly had new meaning. Even periods of illness many decades earlier could be linked to PD. John's breathing difficulties decades before became questioned; were they an early precursor to PD, even did they cause it. Men looked to their biographical histories to explain their illness, but conversely PD could also bring uncertainty to what were previously taken for granted health states, often much earlier in life (Charmaz 1994). Through telling such stories men could try to place their PD within both a wider biographical and embodied story incorporating PD into their lives (Sanders *et al* 2002; Faircloth *et al*

2004a; Reeve *et al* 2010). But in doing so, PD also brought other forms of uncertainty to what was previously a taken for granted story for life.

For John, one of the most important questions he asked was why he had PD?

> *John* *Why have I got it? Why was I selected? I cast my mind back. My father I know very little about health wise. One of the things that always amazed me with my father was that he never saw active service, in the forces, and he was of an age. I always in my mind wondered why, he had a very very nervous disposition, extremely nervous disposition. He shook. He had to be at home, and we wondered if he actually had Parkinson's disease. We'll never know will we. We can't get any sense out of me mum, who's ninety five her next birthday, and completely ga ga. So we can get nothing off her. But my daughter also has MS. Now is it part of the gene breakdown?*

John, along with many others had asked themselves, medicine, and me this question; why did they have PD. Knowing why gave men a means to account for their illness and its inherent uncertainty and could integrate PD into their wider narratives (Frank 1990; Charmaz 1994; Hyden 1997). Questioning why also forced the men to evaluate their lives in moral terms; was PD their fault? Could they have done anything differently? (Williams 1993; Hyden 1997). Medicine couldn't answer these questions with any certainty, but this didn't stop them from asking such questions or coming up with their own, individual and contextual answers. Some could simply accept the vagaries of fate or advancing age as reasons for PD (Solimeo 2009). John came up with his own reasons, wondering if his father's 'shakes' or his daughter's multiple sclerosis might indicate a genetic heritage. Blows to the head, mental health issues or exposure to chemicals earlier in life were also common sources of speculation for PD's origins. All of the men described asking their doctors at some point for a reason for why, being frustrated as they quickly found that medicine couldn't give them an answer.

In sum, men told a variety of stories of their diagnosis, with many of these stories focused on trying to make sense of what was an inherently disruptive experience. But to do so, much of men's earlier lives had to be questioned. To answer questions of when their illness started and why they had it, men had to look to their prior biographies. These biographies also had to a certain extent be remade, questioned as men discovered that the damage causing PD was long term, looking for events signalling when it started or why they had PD. Most of the men tried to answer these questions, but these answers could not be confirmed by a form of medical knowledge which prioritises answering such questions, but currently cannot give them in the case of PD. As a result a certain amount of uncertainty permeated men's biographical accounts of PD, raising questions for both a present and a future self as they lacked a stable, certain platform from which their stories of PD could be told.

Men's stories of medicine and the changing journey through PD.

Men's stories of diagnosis were also the starting point of a wider story, of men's journey through their PD. Through telling these stories, men tried to make sense of the changing nature of their illness and its growing effects on their lives. Medicine's narrative of PD is that of a steady, gradual progression, its symptoms being alleviated by drugs (Duviosin & Sage 2001; Weintraub *et al* 2008a). But men's stories told show up a very different orientation to PD's progression. Moreover, in the lived reality of the lifeworld, the challenges of a life with PD in the future foreshadowed many of the men's acts. Men therefore used their reflections of PD's past progression in order to understand its progression and in particular to negotiate questions about 'how much time they had left'. Through telling stories of their illness, men could draw on their biographical experiences to understand its progression and therefore to anticipate what the future would bring. Importantly, medicine and its practices became

important emplotted resources, used across men's accounts of PD in order to make sense of its progression and where they were on the journey through PD. But to do this, many men re-appropriate many of medicine's various treatment practices, developing their own meanings from them which could often diverge from their treatment goals. By understanding this process, we can gain greater insights into how sufferers themselves understand the progression of their illness.

Using a similar metaphor to Stanley-Hermann & Engbretson (2010), Simon, still in the early stages of PD spoke of his illness as an 'approaching storm';

> *Simon. It's a bit like erm, a bit like a thunderstorm at sea, out of sight of land and you've got a storm, you're very conscious that you're a small boat in a big ocean and that's a big storm, but is it going to hit you or is not going to hit you, or when's it going to hit you and are you going to cope with it when it gets here. You have the impending doom sitting on your shoulder, but you keep going and you keep battling on against the waves in front of you in the hope that the storm will pass or die out or won't be so bad when it hits you. And it's that sort of feeling of this rumble in the corner, when's it going to get me, when's it going to get me, and is that a sign of it. Do you know what I mean?*

Simon's account reflected a future spoken of in similar, almost uniformly pessimistic terms. All the men knew their illness would get worse, even if it could take many years to do so. What they did in the past, they likely wouldn't be able to do in the future. In PD a new, strange orientation to the future becomes clear (Sveneaus 2011). The future ceases to be a horizon open to opportunity, something the present flowed into. Instead the future becomes finite; possessing a clear end point. Unsurprisingly then, it was possible for the future to seem very bleak indeed. But this judgement of the future was the departure for a wider story in PD; how men understood how their illness was progressing (Kleinman 1998; Riessman 1993).

Men drew on several resources to make sense of PD's progressive nature, including those of medicine. For example, medications brought a number of benefits to physical functioning. But men also used their experiences of medications as a '*barometer*', a signpost showing how bad their condition was. PD's individual and highly variable course made it difficult to directly compare symptoms, but medications could be more easily compared; am I taking more or less than you. Medications also became important as points of change in the illness, signifying that their condition was getting worse. As a result medications were imbued with complex meanings. Several examples of these meanings could be seen in men's stories of PD. In early PD, the drug levodopa took on particular significance. Simon was not yet taking levodopa. It was an unknown quantity, but raised significant questions about his future treatment;

GG. *So you're not on sinemet or madopar (brand names for levodopa) yet?*

Simon *No, I don't know what they are. Are they dopamine?*

GG. *They are, they're the levodopa medications.*

Simon. *What I'm not quite sure about, and I'm keen to understand really is this concept of a window of opportunity of dopamine, you start taking it and your symptoms improve slightly, more significantly, but then you need to take increasing doses of it, and then the side effects become to the point where they outweigh the benefits?*

Simon approached levodopa with some ambivalence; it would bring benefits to his condition, but also meant his illness was slowly worsening. In the early stages of PD it was easy to assume that medications could control their condition, now and in the future. Medications led to what Solimeo (2009) calls a honeymoon; alleviating PD's symptoms with little negative effects. But having heard about their potential negative effects, Simon wondered what beginning to take levodopa would mean for his PD. Unsurprisingly then, For Simon, the future prospect of taking medication was

approached with some degree of trepidation; a symbolic meaning intersecting with its pharmacological usage.

Men quickly learned that their medication regimes would frequently change. Almost all the men I interviewed had experienced their symptoms worsening, leading to their dosages being raised or new medications being added. The experience of dosages being raised possessed complex meanings; to be looked forward to because it meant their symptoms would improve. But it also meant that their PD was worsening, that their medications were slowly losing their effectiveness;

> *Tony Yeah, the (the medications) are very sort of erm, time sensitive, and yeah, they only work for a certain period, erm, and when you get the dosage right, then you get hardly any tremor in between the periods, but as, as it wears in, as the year goes on, well I'm down to about eight months now where I need it updating, you know when it starts wearing off, when the dosage isn't enough, you find that the gap between the, you know, when you've got tremor, between dosages is spreading. And you're getting sort of, about fifty percent tremor, and fifty percent not.(...) I've got used to it now, because of what happens when the medication works, you know, when its changing.*

Over time the experience of the 'medication honeymoon' declined, to be replaced by a 'medication window', a different set of meanings in which men knew that the benefits their medications brought would be finite, sooner or later overtaken by their symptoms (Solimeo 2009). But the periods between dosages also became a means for men to measure how quickly their PD was progressing; Tony used the period between dosage increases, and how much the gaps were shrinking to measure how quickly PD seemed to be worsening. There was now a gap of 'eight months' between increases in Tony's medication, making it seem like his PD was accelerating. With experience the time sensitive nature of medications became clear. They would soon 'wear off', requiring further dosage increases. Medications therefore provided a means to

measure PD's progression, but as the gaps shortened, or as their regimes grew, men also had to think about the future implications of their worsening condition.

As men moved through the illness and began to take more and more medications a further question grew how much longer could PD's medications continue to bring benefits;

> *Tony* *I usually hang on as long as I can, thinking that it's finite, you know, somewhere it's got to end, and I don't want it to end. You know, I don't want to go there, and for them to say, I'm sorry, we've run out of medication, that's it. I'm dreading that day but they keep telling me there's still a way to go yet so, ah well just get on with it, there's no use worrying about it, nothing I can do.*

> *GG* *no, but I'm really interested in that sense of you getting that new lease of life, but you know its going to end at some point in the future.*

> *Tony* *Yeah, well you know its going to tail off. I know it sort of comes, usually you know, if it lasts as long as it normally does, and it seems to be getting a bit shorter, erm, it was lasting you know, I could last about twelve months. Now it's sort of down to about nine months when I start noticing it's getting bad, bad bad.*

Tony described a common worry; that medications were growing less effective over time. Men came to question what would happen when they reached the point at which PD's therapeutic treatments were exhausted; they reached the 'end of the medication road'. As PD progressed into a more severe, later form of the illness a further medication grew in prominence; apomorphine, what Henry called *'the last chance hotel';*

> *Henry* *That's the one I'm a little bit fearful of is that apomorphine to be honest. Err, because it always smacks me of the final result as it were, or the last chance hotel, whatever you want to call it. Always strikes me as being, whether it is you know, and I was surprised*

in August when err we went to see, I mentioned the last time, my appointment with (consultant), he said that's the next move, because you can't have any more mirapexin with what's been happening (...). So he said no more mirapexin, it'll have to be apomorphine. So I said if that's what it's got to be, that's what it's got to be.

Apomorphine was thought of as the 'end of the medication road'. When men began to ask such questions each increase in medication moved them further away from a lost period of good health and a little closer to a point where medicine could no longer help them. The point at which men realised medications would no longer be able to provide effective treatments slowly grew closer. Apomorphine became emplotted in several men's stories as the end of this road; a point beyond which no other drugs were thought to be available. Interestingly these symbolic meanings attached to medications were often divorced from the reasons for their use. Apomorphine was thought as the last medication available, but in practice was used to control off periods. Medications therefore were emplotted resources gained by expanding knowledge of PD and used to understand each man's place within PDs progression; how long they had left before PD got *'bad, bad bad'*.

PD and the changing experience of the future; the end of the road through PD

Stories pre-suppose an 'end'; an ending gives form and meaning to a narrative (Ricoeur 1990; Kierans 2005). Stories of illness can be complicated by the lack of a clear end; they are always in a state of being experienced, affecting the stories men tell as they do not now how illness will end; e.g. with recovery or death. However in a commonality occurring through all the men's stories, their lives now seemed finite, the future had a clear end point. Given their experience of PD's progression, men spoke with a degree of certainty that PD would mean they would grow severely impaired, even incapacitated, physically, mentally and emotionally. Such an expectation, based

on prior experience, led to a changing orientation to the future, alienated from both their prior experience and the experience of those around them.

In the face of such experiences, several men chose not to think about the future. As Simon described it, instead they tried to 'live in the present';

> *Simon If I look forward into the future, and think of myself with Parkinson's in ten years' time, it all looks very black. But I don't actually know that I will actually have Parkinson's in ten years' time, I might be six feet under. So what's the point in looking ten years forward.*

When the future has the potential to look so bleak, many preferred not to think about it; to avoid engaging with a future that could easily seem 'black' and hopeless. However Simon struggled to take this position; the future continued to shape his present expectations, for example his expectations of what he could do in the future. A narrative self is a temporal self, men's accounts sought to fit PD into a temporal framework (Ricoeur 1990). Given our three fold experience of time it is impossible for the self not to look towards the future; it is through an anticipated future that we make sense of the present. Therefore, for Simon and for others, living in the present forms an inauthentic orientation to time difficult for them to sustain as the future challenges PD would bring bled into the men's presents; seen in Simon's earlier account of the future as an approaching storm.

If men did speak about the future, it was commonly as an object of fear. A single fear was most common in men's stories of a future living with PD; that they would eventually 'have to go into a home';

> *Henry I would be horrified, and this is a double ender really for me, I would be horrified to go into a home. (...) I've been, I've visited people in homes and all the rest of it, and quite frankly, and one of the homes that I went to was one in (local town), which is reputed to be*

one of the best of the care homes, yes. And you sit there and you look at the people that are there, and they're blankly looking at the TV, or they're snoring in the corner, or they're just sitting there, you know. I'd think to me the only description is they're waiting to die. And err that's what happened with the fella I knew. He went into the home, he became a different person. Erm you'd talk to him, some day's he'd talk back to you, other days he'd just look at you. I honestly don't know how I'd react if I found myself in that situation.

Residential care came to symbolise David's, Bob's, Tony's, Henry's and even Simon's fears. Given the importance to a masculine self of being independent and active; themes reflected throughout men's stories, the space of the residential care home was opposite to how several men judged a worthwhile life. In residential care they would be immobile, but more so they would be inactive and bored, the opposite of a self they wished to portray (Meadows & Davidson 2006).

In the face of a future with incapacity, some of the men found themselves talking about death. In what became an often difficult topic for men to talk about, and for me to hear, several spoke of death being preferable to experiencing the worst effects of PD. For Tom and Bob, both in their 80's, the hope was that they might die of something else before PD's worst effects hit home;

Bob. If I'm lucky I'll die of something else, before Parkinson's. No, quite happy to go (laughs) it's just I hope I go out with one bang, that's all.

Such a hope could be oddly comforting and for those in older age, preferable to living with PD in the worst stages. Such fears came from their earlier experiences, but also their expectations, based on their knowledge of PD and experience of seeing others deteriorating. Instead of the unavoidable end of life, Bob, Tony and others spoke of death as a potential escape from PD, a way of avoiding its worst experiences.

The idea of death being an escape from PD was not limited to older men. Younger men also spoke of death, but in a slightly different way. Unwilling to experience what he thought would be the worst excesses of PD, but knowing that he was still relatively young and could expect to live even several decades with PD; Tony instead spoke about *'going to have to make a decision'*; of planning for suicide at some point in the future;

Tony *It's going to reach a stage where you know, well, well, plan A is I'll get run over by a bus, or something will intervene before it gets that bad, but obviously, if I don't snuff it before it gets ridiculous, then I'm going to have to make a decision. Somewhere along the line, and as I think I've told you before, there's no way I'm going in a home, so you know. Ideally it's a cardboard box at the top of the field. (laughs).*

GG *Right, and is that something that's frightening, scary?*

Tony *Err, now and again. Most of the time I think, yeah, it's alright, you can deal with that. If life's that bad, there's no point in bloody, I don't want to end up somewhere sitting in a corner, you know, looking at a telly that I've not looked at for forty years, dribbling, dribbling and twitching. No, that's not for me, and I don't think I could live with, you know with other people, in a home or anything like that, so its err, yeah. I hope something takes me out first. Basically, if it doesn't, then as I say, I'll have to make a decision. Most of the time, I think, yeah, okay, you've made your choice, that's how you deal with it.*

GG *What is that decision to be made?*

Tony. *Well basically, I've got, I'd kill myself. Yeah. Oh I'm not going to do that tomorrow. It's not a depressive thing, it's a, if you like it's a life decision, if you can make a life decision about death. I don't know. Its err still being in control, I think is the expression. (...) I would swan up to the top of the field in winter with a bottle of scotch, and a few tablets, its cold enough. You wouldn't feel a thing, exactly. Exactly.*

Given prior experiences of PD worsening, and his perception of the speed it was progressing, Tony spoke of reaching a point where he would be unwilling to put up with life with such a severe level of disability. But interestingly, Tony also found such talk strangely liberating. Death becomes a *'life decision'* under Tony's control. Through suicide, Tony chooses not to experience PD's worst effects. This judgement was made in a threefold manner, Tony understanding the future through his prior experience of PD, which then informed how he anticipated his PD to continue.

In sum, all men faced changing meanings of the future. Based on their previous experiences, men knew that their condition would worsen, changing their view of the future from one open to possibility to a future closed and growing increasingly limited as men's abilities declined. But men could find different ways to emplot these expectations of the future within their current narratives. Some chose not to engage with the future. Others hoped that they would die from something else, or simply due to old age before PD's worst effects took hold. And some tried to make plans, looking for ways in which the fears of the future could be lessened, for example by making plans to commit suicide before PD's worst excesses took hold. All these thoughts about the future could and did change as men moved through PD, as men gained new experiences and as their expectations of an increasingly impaired future drew closer.

Summary

Lived time and its experience was also constituted through each man's wider stories of his life, using their earlier experiences to project themselves into an unknown future. The prior experiences and stories men told of their PD were used to inform their expectations and anticipations for the future, changing its meanings as they looked forward with uncertainty and fear. In PD the future becomes a clear object in the

men's lives; something they must engage with even if this is choosing to ignore it.. The past also changed; the memory of a past life of good health slipping further away into memory but also becoming remade as PD forced new recollections of past experience. In addition, these accounts continually changed as men moved through the disease, as their symptoms changed, and as a healthy past grew more distant and men's anticipated future drew closer.

These stories have key implications for men's experiences of medical care. Stories of PD were inseparable from stories of care. Medicine played perhaps the greatest role in men's attempts to make sense of their PD, providing resources through which PD came to be known. Most men used a medical language when talking about PD; to describe its symptoms or its medications. However the current biomedical narrative of PD cannot account for many crucial lived experiences; not least men's attempts to understand when their PD started and why they had it. In the absence of a clear medical narrative for PD, men continued to tell stories about their condition; trying to understand PD's incoherent experiences using their own resources and according to their own individual contexts (Pinder 1992; Mattingly *et al* 2011). Medicine continued to play a role in this experience, most clearly seen in how men spoke of their medications, using them to understand the progression of their illness. These meanings could diverge from medicine's purposes, creating tensions between the clinical goals for PD's treatment and the men's everyday meanings. As seen in men's stories of a temporal self in PD, narrative is central to our experience of lived time, recreating a temporal context lost in the face of illness, trying to give new meaning to life's changing experiences and their changing future expectations (Hyden 1997).

Conclusion

In this chapter I have described some of men's changing experiences of lived time in PD, and the role narrative plays in this experience. For men with PD the everyday meanings of time no longer meant the same as they did, lost as the body could no longer navigate the temporal horizons of the lifeworld in a taken for granted manner. But as these structures fell by the wayside, new structures rose to take their place. Men experienced a break from their prior everyday experience of lived time, potentially disconnecting them from an inter-subjective lifeworld. And in a further dimension the meanings men held for their prior lives, alongside their expectations for the future also shift. Life becomes a life lived with illness, leading to whole new ways of recollecting the past and anticipating the future. Finally men also told stories to make sense of their experiences of medicine and its care, to understand its effects on their illness and on their lives. By telling stories, men could try to make sense of often incoherent experiences and to construct a new sense of self (Hyden 1997; Charmaz 2002).

Mattingly (1994; 1998) discusses the role that therapeutic emplotment has in the treatment of illness; how illness sufferer's and medicine respond together to construct the practice of care, promoting care by creating joint stories about illness and its recovery (Del Vecchio Good *et al* 1994; Tropea 2011). Men emplotted their experiences of a variety of medical practices, using them to understand a constantly changing condition. Stories about diagnosis are stories about medicine; about the role played by clinicians in helping or indeed hindering them in their attempts to live with the disease. Medications possess symbolic meanings, but they are also emplotted and embodied meanings; experienced through their bodily effects, but also used to impose a coherent structure on PD's changing temporality (Hyden 1997). A key question

becomes the role that medicine plays in the construction of these narratives, and are they produced in conjunction with, or as a consequence of men's encounters with medicine. Do the stories men told of PD evolve in conjunction with, or in opposition to medicine and its practices (Tropea 2011)?

Given the lack of a traditional medical narrative of recovery within PD, that men would receive continued, individually attuned disease management was the best that could be hoped for (Pinder 1992; Charmaz 1999). The goals of PD's treatment shape its emplotment; for PD's treatment to be successful, how men developed a narrative for PD in conjunction with their various clinical professionals is an important issue. Men use their own knowledge to develop their own stories of PD, doing so using information gained from their clinical encounters. But in the absence of such information, men also try to make sense of PD, using other sources, or giving alternative meanings to their medical treatment. For men to make effective decisions about PD's treatment, and moreover, for them to incorporate PD into a biographical self, greater attention needs to be paid to how men seek to emplot their clinical encounters, either with or without the assistance of their clinicians within the clinical encounter. In addition PD is continually re-emplotted, its meanings changing as men move through the illness and their experiences, both of PD and of medicine change Medicine has a continuing role to play in PD's lived experience beyond simply providing treatment. Its role, the information it gives to patients, and the concerns that it seeks to address should also change as men move through the illness and as their various needs evolve. Attention therefore needs to be paid to PD's experience throughout its illness trajectory.

In conclusion, lived time and its comprehension through narrative is a key element of PD's lived experience. By telling stories about PD's changing experience, men could

attempt to incorporate PD into their lives; to make sense of its disruptive experiences. However PD, in its uncertainty and its progression, meant that these stories continually had to change and evolve, changing shape as PD's symptoms worsened, as a past of good health moved further away and the 'approaching storm' of a future with potentially severe disability grew closer. All these experiences threatened to distance men from their wider lifeworlds both as time lost its everyday meanings, as new structures rose to take their place, and as the time narrative experience held different meanings. Crucially medicine plays a role in this experience, however in current neurological approaches to PD's treatment, not enough attention has been paid to how sufferers engage with medicine and its practices in order to develop narratives for their condition. By paying closer attention to how PD is experienced as a 'temporal' illness, and to its therapeutic emplotment; how men tell stories about their clinical care, medicine can assist men to reconfigure their stories, and therefore promote well-being in PD (Mattingly 1998; Tropea 2011).

Chapter 7. Men's accounts of living and coping with PD

Introduction

In the last two chapters I have concentrated on men's accounts of the problems of PD; problems most keenly felt through the experience of the lived body and its place within the flow of lived time. But this was only part of the stories men told about their PD. All the men could respond to PD and its effects, drawing on their everyday experiences in order to incorporate PD into their lives. Within the study of PD how men respond to PD and its effects has been studied via predominantly psychological approaches concerned with the question of 'coping' (Ehmann *et al* 1990; Hermann *et al* 2000; Hurt *et al* 2011). Defining coping as utilising any behaviour or thought to respond to physical, psychological or emotional stress, a number of studies have sought to apply existing models of coping to PD, for example demonstrating which models are either beneficial or maladaptive in PD (Lazarus & Folkman 1984; Lazarus & Lazarus 2006; Hurt *et al* 2011). These studies have told us much about the effects of coping on quality of life, for example by showing that active, problem solving approaches to coping in PD are more beneficial than those focused on avoidant or emotional forms of coping (de Ridder *et al* 2000; Hurt *et al* 2011). However this body of work tells us little about the practice of 'coping'; how PD sufferers 'do' coping, what it means to cope with PD and finally how men with PD, through their stories of coping seek to negotiate a disrupted sense of self. Rather than being concerned with the effectiveness of any particular model of coping with PD I am instead interested in the practice of coping; how men seek to cope with PD through their everyday act, and how through these acts they seek to negotiate a changing lifeworld. My goal in this chapter is to therefore consider the stories men told about coping, their accounts of their acts

in these stories and ultimately what these stories tell us about PD's lived experience (Bury 1991).

I focus on five major thematic areas, each emerging from the men's accounts and each focusing on how men responded to the various challenges PD brought to their lives. First I examine how men dealt with their changing embodiment. After this I examine a specific act men engaged in in trying to understand their illness; seeking information, advice and support in their attempts to understand and respond to PD. Third, I examine how men tried to cope with a changing experience of lived space, in particular how they reconfigured the spatial layout and meanings of the home. In part four I examine how men dealt with changes to their family relationships and the growing experience of care. Finally I examine men's wider experience of the social world; their relationships with friends or their passing contact with strangers, and how men dealt with their newly problematic nature. To conclude this chapter, I consider how, through these five themes emerging through men's stories of PD, the majority of men enacted strategies to deal with their illness, and through these acts, tried to negotiate a changing biographical self positioned within the lifeworld.

Part 1. Dealing with a changing embodiment

As discussed in chapter five, PD leads to fundamental changes in the experience of the lived body. Movements ceased to be natural, transforming a pragmatic embodiment as men began to struggle with the simplest everyday tasks. The effects of medications forced the body to live according to new, often distressing cycles of bodily functioning. These problems challenged the most taken for granted of men's activities; walking, talking, picking up objects, eating and sleeping. But importantly, a central theme of many of the men's accounts of a changing body was to show that they could still do

things. Despite PD they could still accomplish many of their everyday acts. Central to many men's accounts of their changing bodily abilities was that they could find new ways of 'doing'; discovering new ways to complete their many everyday activities. But to do so, several men found themselves having to learn a whole new way of attending to the body; what Dafydd described to me as learning to use the body '*in a different way*';

> *Dafydd Erm, it was wiring a plug, that's the simplest thing in the world, wiring a plug. But because of the way I couldn't grip properly. I mean I had to find all sorts of ways of manipulating the screwdriver, very frustrating. Over the years I think I improved, I can still put a wire in a plug, purely and simply because of what I've learnt. What I've learnt is that the body, and the brain, can be trained to organize a job, to do it in a different way.*

Dafydd later expanded on what he meant by this;

> *Dafydd Erm, I think I've spoken very briefly at one time to you, to (consultant) about this problem. He was mentioning about erm, training your brain to sort of work through different channels or whatever I don't know much about it. And by that I understood what he was trying to say was that the brain tells the body parts to do what they should be doing, if that makes sense.*

For Dafydd the old ways of using the body no longer worked, but his body could be 'trained' to do things in new ways. Dafydd's experience indicates a new, changing orientation to the body. In chapter five I discussed men's experience of a body forcing itself into men's awareness; a body men found themselves increasingly having to thin about and feel. This new orientation to the body also gave men a means to continue to use it. Activities could continue to be achieved, but men quickly learned that this could only be accomplished by holding the body in near constant attention; by focusing on the body and the stepped, routine movements it needs to make to complete any activity. Peter spoke to me about his new experience of handling cups. Peter could

manage it, but needed to think about the act in new ways. In particular, he now had to tell his hand to let go:

> *Peter* *When we have drinks she can't carry them, so I carry them in, and what I find interesting in, whenever I'm holding something. Now I used to just let go, I mean I'm looking at her now alright, but sometimes he doesn't let go, I have to say 'let go hand', so to speak, I don't actually say it (laughs) you know, you'll be giving me funny looks! But it is so, sometimes I have to put that through like that. I don't know if that helps you at all.*
>
> *GG.* *No that's fascinating, so sometimes you have to...?*
>
> *Peter.* *Yes, that's right, it just delays it, push that finger back. That's the only thing I can think of, but it's definitely different.*

Peter gave me a detailed account of how he now engaged with a changing body. The body seemed to need instructions; to be told what to do and how to do it. This experience also extended to the body's use of the various objects found throughout the lifeworld. Bob explained to me how he now had to use the variety of tools associated with his working life;

> *Bob:* *Erm (2) I'd been a keen repairer of various electronic things, and I found that at times I couldn't get erm, components to put onto a printed circuit or anything. And even worse trying to solder them, because the way I was getting err, through with it was to use my right hand to steady my shaking left hand, and of course with the soldering iron I can't use my right hand to hold it, but by today I can, simply because I use long nosed pliers, on two shafts of the soldering iron, so I can hold it. But then again I don't have three hands to put the solder on, so it's getting difficult. Also erm, combined with all this I've been doing all the electrical work, all the technical work myself, and err, I find that anything to do with fixings above my shoulder, be it on a step ladder or on the floor, was erratic, I couldn't get screws into the ceiling or anything like that, well yes I did because I used to be using brass screws, I used steel screws with a magnetic screwdriver, which, trying to get over things in*

that way, and I'm still doing it actually, as much as I can. It's getting harder and harder, erm, (2), right I've just been getting on with anything I do

To achieve their tasks men now had to think about and through the body. Simple activities; picking up a cup or using a screwdriver could be broken down into a series of steps, each involving a different series of bodily movements; telling the hand to pick up a screwdriver, slotting it into a screw, applying enough pressure to turn the screwdriver and screw. Instead of just 'doing' now the movements and effort for each act had to be considered. Importantly the body could potentially 'go wrong' at any of these stages; perhaps Bob's hand shook, stopping him from slotting the screwdriver into the screw. Or he might suddenly lack the strength needed to make a screw bite into the wood. But through innovative problem solving, thinking about the movements of the body and the sequences in which acts were completed, men could find new ways to do things. Bob's coda was that despite his difficulties he could still use a screwdriver; Bob could still *'do as much as I can'*. Men's acts could be sustained, but this needed this new orientation to the body; breaking an activity into its various stages, thinking about circumventing any problems at each stage, and paying far more attention to the intentional actions of the body.

In a further embodied experience, men found that their bodies could suddenly disobey their actions; moving of its own accord or in the form of freezing even refusing to move. But men could also find ways to deal with what they saw as an increasingly recalcitrant body. Men commonly spoke of finding 'tricks'. Alternatively the body could be 'forced', made to do things. In both accounts, men could find ways to cajole or force their bodies into movement, making it do what they needed it to do. Men had numerous examples of such experiences. Dafydd frequently experienced freezing, but could 'trick' his body his body to overcome it;

Dafydd *Once I've froze I'm stuck, but then I started, I don't know how I've doing it, but sending messages to my brain, to tell my foot, that if I go back, and then swing forward it'll move. And it works. Seven times, seven times out of ten. And I do think that maybe that I've found something to free me*

Dafydd could unfreeze by '*sending messages to my brain*'; by 'telling' his foot to move. Others spoke of freeing themselves by either imagining a line in front of them or by making a loud noise. When shuffling, Henry could 'stretch', temporarily returning his walking to a reasonable gait;

Henry *you know if I'm shuffling and that now, I'm stiff in my back, I touch my toes a few times and do stretches on the wall and that, count my steps, you know, and then I'm probably walking alright again. Like now, this time of day, not later in the day. But err, they don't cure it, they help. You know, they don't cure it.*

Henry could also override a shuffling gait by marching, by counting a rhythm and walking to it. Tricks could also be used to hide the more visible of PD's symptoms. A tremor could be hidden by picking up an object or holding something, pretending to do something, even squeezing a tennis ball.

Medications also became an important tool to control the body. The often immediate effects of medications could be used to give men a 'boost', felt in both their physical movements and their bodily sensations. Fearful of potentially losing his driving licence during a health assessment with the UK driving standards authorities, Ian described '*overdosing*' on his medications;

Ian *When I knew I was going for my driving assessment, which was a fortnight ago. I took my medication as normal the day before, and I went to bed about midnight, half past twelve, and I was up at four o clock, took medication again at four o clock, so that there wasn't a big gap, a big night gap, took it at four o clock, and I took it again at quarter past eight, ready for my assessment at quarter past nine, and I was bang on. (laughs). The*

tremor had gone, and my speech was good. In fact there wasn't a problem; you wouldn't have thought there was anything wrong with me.

Medications were used to explicitly disguise men's bodies, to hide their symptoms and create an illusion of better functioning. For Ian and for several other men; Roger, Simon and Dafydd included, driving was too important an activity to lose. It was therefore worth Ian manipulating his medications to ensure he was performing at the best of his ability. Doing so could have costs, overdosing could lead to them moving too well, leave them feeling hyper, or could lead to later fatigue as they over-exerted themselves. But it was usually judged worth it, either as a means of 'getting them out of trouble' or so they could do what they wanted or needed to do. Through various forms of subterfuge, men could find ways to make their bodies move or could hide the 'true' abilities of the body, again illustrating a wholly new way of having to think about the body, an obstacle the men now had to 'trick'.

In a final new orientation to their bodies, men could find other ways to 'train' the body. Given that men's bodily abilities were seen as a finite, declining entity, part of maintaining their abilities was by finding ways to exercise the body's physical and mental functioning. Several men described doing puzzles, crosswords, jigsaws and other mentally stimulating games; all seen as ways to sustain their cognitive abilities. Given the fear that cognitive decline was a common, even inevitable part of older age, such exercises were seen as a means to maintain their cognitive abilities. Even more common was the importance of physical exercise. Almost all the men noted the importance of staying fit, strong and active; all of which can also be thought of as ideals of an embodied masculinity (Monaghan 2001; Tulle 2008). Even Tom, who needed to use a wheelchair much of the time noted the importance of staying active;

Tom *I must get fit on there (his bike), and I'll go three or four days missing it.*

GG *What's important to you about going on the bike?*

Tom *Keeping fit. Keeping active. Not so much fit, it's just active.*

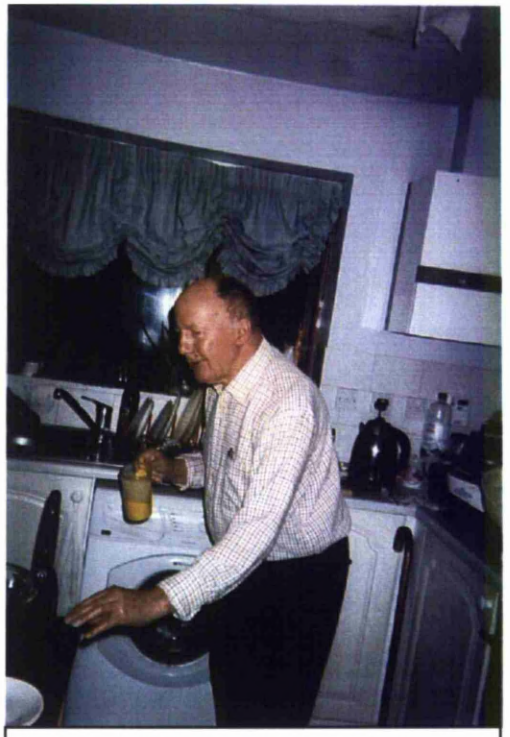
GG *And what's important to you about keeping active?*

Tom *It keeps you out of a home. (laughs). Well its erm, there's so much you lose inability, once you stop using it that's it isn't it.*

Harold regularly received physiotherapy, but called it a gym; associating it with fitness and exercise rather than illness and therapy; describing these sessions via what were more acceptable meanings (Calasanti 2010);

Harold *I go to the gym on a Tuesday morning, I've not been this Tuesday, but. My backs been a bit worse, so it's been a bit trying. I also go to the Parkinson's, like a group, and we do some exercises there. It gets quite hectic really, you move from one to the other, so for about an hour and a quarter, an hour and a half, you do exercises, which I find it helpful. I'm sure I'd be a lot stiffer if I didn't.*

Exercise was important allowing both Harold and Tom to maintain masculine bodily norms about being physically fit and therefore healthy. But 'training' the body had a more important element to it. As Tom notes, exercise was about being fit, but more so was about being active, or more accurately staying active. Tom put it simply but eloquently; '*once you stop using it that's it.*' Tom explicitly exercised through the fear that if he stopped, he couldn't be able to start again; 'use it or lose it'. Exercise was a means to maintain bodily suppleness and flexibility; at its most basic, through exercise men could sustain the basic ability to move. David spoke of the fact that he seemed to want to do less; something he associated with old age, and therefore had to fight;



Photograph 13 Peter carrying a cup of tea

David *Well I've still got, I've still got life in me. I want to get better, I want this, I want that, I'm not satisfied with just existing, or giving up. (...) My grandmother used to sit in a corner, with a shawl around her neck, my mother would have dearly loved to have been the same, but she wasn't allowed to be, and she was ninety four, and err, my nieces are doing the same with me, they are not allowing me to sit in a corner, and I think that the people, I always mix with younger people, I've always done that. And it keeps me young, and interested in what goes on.*

GG *You say your friends won't allow you to sit in a corner.*

David *That's right.*

GG *Would you like to just sit in a corner?*

David *No. But if I did, nobody would move me.*

GG *Right, forgive me if I'm putting words in your mouth, do tell me if I am, but it does sound like there's a part of you that would do that if you were allowed to.*

David *Partially. But it wouldn't happen straight away. It would be a slow process developing. Developmental process. If there is such a word.*

Men had to fight both an ageing body; *'my backs been a bit worse'*. But PD also made men's physical activities harder and harder. If left to their bodies, David feared he would grow increasingly immobile, even lazy. Exercise becomes a further resource, used to fight the inertia that PD could bring; something their bodies could easily accept if allowed to. By speaking of training the body men could therefore show that they remained active, but this activity now had to be worked at. In talking of exercise in this way, not only could men stay active, but they could also fight both their ageing and their PD.

However men's new ways of attending to the body faced continual change. During my first interview for PROMS-PD Peter could carry cups of tea relatively easily, by walking slowly and taking his time. Two years later in these interviews Peter could only carry cups one at a time; half-filling a cup so he wouldn't spill its contents (photograph 13). But in my final interview four years after first meeting Peter he could hardly carry cups at all. Flux was the new norm for men's bodily experience. The men's various forms of tricks would work for a time, but would eventually lose their effectiveness. Men could try to remain as active as possible, using their stories to show how they did so. But men also had to acknowledge that they were slowly becoming less active; they were finding activities gradually becoming harder. All had to acknowledge that they could no longer do what they could do a few years, even a few months ago. Phillip had neurosurgery 18 months prior to my interviews, after which he experienced a rapid improvement in his symptoms. But 18 months later, he was once again losing many of these abilities. New medications or treatments could mean lost abilities could suddenly

be regained, but in all likelihood they would be lost again. As flux became a new norm for bodily experience, men simply couldn't 'get used' to their declining embodiment.

In summary, PD required men to become more and more aware of their bodies and of their pragmatic embodiment (Robertson 2006b). But this experience also provides the basis of a new form of embodied experience; where by thinking of the body as an object, men could find new ways to use it, and through these uses to maintain a masculine, active embodiment (Hoglund *et al* 2009). By attending to the body as a conscious object; a body that could be tricked and that could be trained, men could find ways to accomplish the movements needed to perform their daily tasks. But this re-incorporation of the body into the lifeworld required the body to remain in men's constant attention, further reinforcing its dys-appearing state as men had to think about their bodies in their simplest tasks. And furthermore, despite all the above acts men still found that *'everything's getting harder'*, ultimately all they could do was forestall PD's decline. Any new ways of using the body had to be constantly revisited, vulnerable to PD's progression, meaning that men's forms of adapting to PD would eventually fail. As a result, men could continue with their activities but only through a continual, awareness of their changing bodily states; despite men's acts the body could never return to an absent embodiment.

Part 2. Seeking information and advice from medicine

All of the men I interviewed spoke at some point in their interviews of a desire to receive information, advice and support about their PD. 'Information work' has been described as an expected part of living with a chronic illness, in which information is used for a variety of purposes. Not simply seeking to find out about PD, men used information to maintain their health, to improve their wellbeing and to sustain a

coherent sense of self (Habermann 1996; Whitney 2004; Phillips 2006). For most, it was medicine that acted as their first point of contact for information about PD (Seale & Charteris-Black 2008). David spoke to me about the information his doctors provided;

> *David. these people, if you analyse what they say it's all textbook stuff, yes. It's not actual, that's the way I feel anyway, (...) I was a teacher, and there was a new method of teaching coming along. I would look at it, I would read about it, and I would implement it, but at first, because I've never had that many people with Parkinson's, there aren't that many doctors that read about it, to the same extent as they would if they met it every day, and it's becoming increasingly more, they're diagnosing more and more of it. Erm, so they have a knowledge in inverted commas, but not in-depth knowledge, which I don't expect them to have because they have so much of their own specialty to learn about, but that's the sort of thing that I feel anyway. That I could do with more advice, or that advice be available.*

Many were satisfied with the information they received from their doctors, however some, including David found the information provided by medicine to be problematic. David faced a number of dilemmas including when to move from his current home; a lived dilemma many with PD will have to face. However David felt medicine could only provide what he called *'textbook knowledge'*; it couldn't give him the in-depth, individual and contextual knowledge he felt he needed to manage his own illness (Mattingly 1998). Information about symptoms could be imparted via a biomedical model, with many finding out about PD's symptoms in this way. But in most men's experiences, their clinicians struggled to provide nuanced, flexible and individual information attuned to men's needs. Several also found that medicine also struggled with many of the practical issues of managing their PD. Most found that their medications had to be learned through a process of trial and error;

GG *That timing, how do time your tablets.*

Dafydd *Well its timed by trial and error, and its over a period of years, you can't do it over night, and you've got to be very, erm, what's the word, erm, observant, so you know that they'll do a certain thing, and you'll tire quicker than other things.*

For Dafydd this process had had positive benefits, but had taken a long time to determine the best dose, requiring him to work in partnership with his doctors to work out what was best for him. Here men had to face both further limits to medicine's formal knowledge and the fact that they also had to play a more active role in PD's treatment. Several men quickly had to face not only the limits of a medical knowledge that could not answer many of their questions, but also that they had to themselves work with their doctors as part of their treatment; playing a more active role than they might otherwise had expected. Some, including Simon leapt at the opportunity to be more involved in their clinical care, but others, such as Bob struggled to deal with this experience. In addition, others had problems accessing their clinical staff, several noting it was very difficult to reach their PD specialist nurses for information. More closely involving men with care could therefore only take place if men's clinician provided men with useful forms of support, something that could be problematic when medicine failed to give men what they thought of as information and advice cognisant of their lived experiences or in some cases simply failed to be there at all.

Men's desires for information also changed over time, requiring different responses from medicine. Diagnosis was the first point at which men sought information. But some men had different reactions. Simon wanted information about PD almost straight away. In contrast Roger and Dafydd initially *'didn't want to know';*

GG *initially when it first started you said you didn't want to know.*

Dafydd. *Yeah.*

GG. *What do you mean, you didn't want to know?*

Dafydd *Well, I didn't want to know what was round the corner, and what the future was (inaudible for 3 seconds), that kind of thing, I just thought it won't happen. I was coping, it hadn't been different. I mean if I had have been shaking, that sort of thing I might have thought about it differently.*

Instead it was Dafydd's wife who sought information about PD, informing her husband later in the illness once the disruptive experience of diagnosis had settled. However, most eventually came to recognise that they needed some knowledge about their condition. As discussed in chapter six, John and several others sought answers to the question of why; used to try to make sense of why they had PD, and therefore to try to integrate it into their past biographies. Men also wanted information to try to understand the detail of their illness; what Simon described as *'understand(ing) the benchmarks'*;

Simon *Well the difficulty for me really is understanding the benchmarks. It helps me to look at it in a perspective. Because I obviously don't have previous experience of the disease, I haven't got anything to gauge it from. I'm also aware that people don't want to frighten me by telling me what's round the corner, I mean the big bad wolf's going to bite just the same whether you know he's going to bite or whether he doesn't bite. It's still going to hurt the same. And that's the view I take on it really, the pain is going to be the same whether its coming or not, but if I know it's coming I can offset the pain because I can take bigger steps to deal with it.*

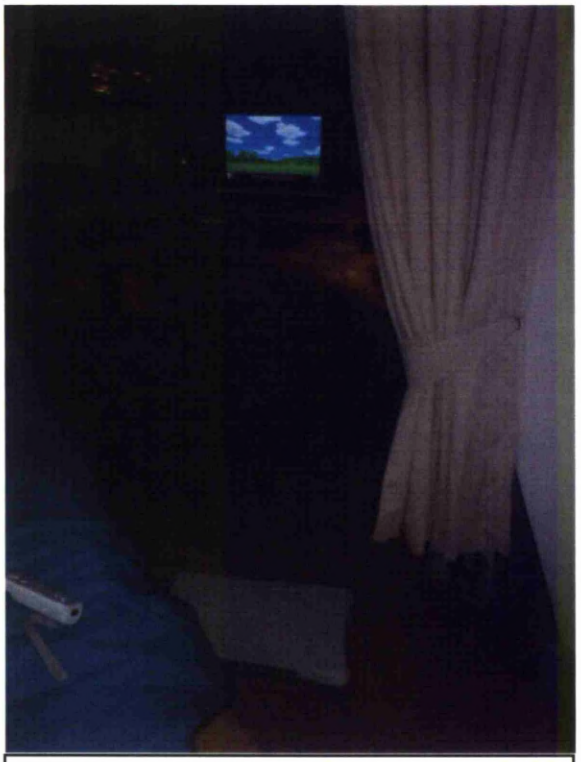


Photo 14 Simon's TV, Wii video game, 'Wii remote' controller and 'balance board' peripherals

Simon. I've talked to you before about the wii fit, that's another strategy for keeping it at bay, and its helping my posture, my walking considerably. Not just the technical aspects of understanding balance, which obviously has been a big revelation. Knowing how well, or how poorly my posture was, I'm able to correct it, and correcting it has helped my walking and helped me to focus on decent posture.

Simon wanted to understand the basics of his illness; so he knew how to '*gauge it*' in himself, compared to medical descriptions of PD and to other people. Importantly, seeking information had a practical purpose. Simon could use information from his doctors or other areas to develop his own strategies for dealing with PD. For Simon, gaining knowledge about PD had been a 'revelation', leading him to question many of the ways he had previously understood his body and his health. This information could then be used for applied goals. Using the Nintendo Wii, Simon developed a series of exercise regimes based on what he had learned both from his clinicians and from

taking part in research studies, which he used to improve the movements of his body (photograph 14). He could also use this knowledge to 'chart' his own symptoms, using a particular game to monitor changes in his balance. Finally, by seeking information in this way, Simon could also position himself in relation to his doctors. Simon regularly took his Wii to clinics and to support groups to show both his doctors and other patients; setting himself up as an 'expert' on PD in relation to others. By using information in this way, Simon such develop a range of strategies for dealing with PD; a practical, goal oriented approach to information seeking which also assisted him in positioning himself in relation to the clinical encounter (Seale and Charteris Black 2008).

As PD worsened, men's desire for information could also change. In later PD men spoke about practical issues; when and how they should transfer power of attorney, or what benefits or social care support they could get. David spoke to me about whether he should move from a home now too big for him to easily cope with;

> *David* *I'm between two minds, have I come to the stage, and this is the thing I've got to solve for myself, have I come to the stage that I need to move out of this house, cos it's a big house, its brought a family up, and I like it here but would it be better for me to be in a smaller house, or a flat, or err, into a home.*
>
> *GG* *And what are your feelings about that, about the prospect of leaving here?*
>
> *David* *Dreadful, I don't want to. Because I've had thirty years, forty years here, of happy life, but if it's got to be done it's got to be done, that's the sort of person that I am, once I've made my mind up, but what I can't make my mind up about, which avenue to take, and this is where I think we could do with some advice.*

David's excerpt illustrates how men's information and support needs changed as PD progressed. But his account also revealed how for men, talk of practical concerns could

also give men a means to talk about more difficult, often emotional issues. In what turned into a very emotional part of his interview Ian spoke about his various household tasks;

> *Ian I erm, I rang the social services oh months and months ago, to ask for someone to call, and I'm still waiting. I never chased, I never followed it up, I'm going to have to because they don't have home helps anymore, well they do, but they don't do any home helping. They come and hold your hand and make you a cup of tea. I need to get hold of a cleaner, or a company that does cleaning, but unfortunately they charge such ridiculous rates, twelve pound odd an hour. I'm a tradesman and I never got twelve pound an hour. (Ian becomes tearful). But it's the physical demand of doing things that I can't cope with. Things that you wouldn't give a second thought to when you were fit, but now I have to think, how can I get round this, and how can I get round the other, and how can I do this, and how can I do that, I've got to be thinking all the time, to err, to work out solutions, and I tried putting a bell on the front door, that's as far as I got, it won't work. I've had it on and off, and on and off and on and off and I can't get it to work at all*

Ian starts with a pragmatic account of his difficulties. But Ian started crying when talking about the difficulty of managing his everyday tasks. A former *'tradesman'*, fixing a doorbell, something he should be able to do easily was now too difficult, something extremely upsetting when framed against his prior abilities. Ian's difficulties, questioned his independence; admitting that he needed help was something extremely difficult for him to do. But having acknowledged this need, Ian found no help was available, leaving him with no recourse but to struggle along, trying and failing to cope with a world growing difficult to cope with without outside help. It is a common claim that men discuss instrumental concerns as a form of emotional distancing, focusing on practical activities rather than their emotional distress (e.g. Sanders Dewey *et al* 2001; Seale & Charteris Black 2008). However David and Ian's accounts demonstrate men's desire for information and support was far more

complex. Information could be connected men's expressions of the self as pragmatic rational individuals; seeing information to help them manage their condition and to position themselves in relation to their doctors. But it could also be a means for men to help deal with often difficult emotional issues, indeed in Ian's case seeking information about services which could provide assistance in the home could be interpreted as a cry for help. If such a cry for help went unanswered, as Ian attempted to show in his account; this could have negative consequence for men's well-being.

In summary, seeking information and advice about PD was a key act in men's attempts to cope with the various challenges brought by PD. In order to best respond to their illness, men needed to become informed; to learn about their illness and what it would mean for them now and in the future. Men's desire for information could be emplotted in various ways. Men sought information in order to incorporate PD into the biographical flow of their lives (Faircloth *et al* 2004a). Others wanted to 'know' about PD was so that they could 'know what they were dealing with', so they could 'know their enemy' (Charmaz 2002). Some wanted information in order to find solutions to their condition. And a few sought information as a cry for help; a means to do emotion and talk about often distressing experiences but in ways which were judged more appropriate to men (Robertson 2006b). But men's attempts to seek information from medicine raised a number of dilemmas. In particular, several men questioned the form and type of information, and therefore wider support that medicine could provide. Where men, such as David felt that their doctors could not give the personally attuned information relevant to their lived experiences, this questioned their wider relationship with medicine. In contrast those men who felt medicine could provide information they could use in practical ways could find ways to more positively cope with their PD. As a result, medical practice, alongside wider

support mechanisms can do much to help men to cope with PD through the provision of information. But this must take place in ways cognisant of how men use information, what its receipt means for men, and how, in seeking information about PD, the individual ways in which men seek to position themselves within their changing lifeworlds.

Part 3. Reconfiguring the home

As discussed in chapter 4, men also faced various challenges within lived space;

> *Hugh Sometimes if I go down to (town) to do a bit of shopping, and err, it (PD) will creep on while I'm down there really. I'll just leave everything and go home. I've walked out of the shop sometimes, I can feel it coming on, so I will just jump in the car and go home, and wait for the medication to kick in, and go down later to do the rest of the shopping.*

Given that accessing public space was becoming harder and harder, several men found themselves spending much more time at home. Like the body, men's experience of the home, along with its subsequent meanings was also becoming remade. Home has been described as a haven for those with chronic illness, secluded from an outside world growing harder and harder to manage (Sixsmith 1990; Nijhof 1996; Mowl *et al* 2000; Milligan 2005). When the outside world was becoming harder for the men to be active within, the home became a place where they could possess some form of control over. However many men also found themselves experiences a number of problems in the home (Milligan 2005). Simon spoke about needing to '*minimise the dangers in the home*';

Photo 15. Simon's gate at the top of his stairs

Photograph 16. Tom's rope and pulley system

Simon; Another one is to minimise the dangers in the house. Erm, as you know I've had a couple of doors fitted in the kitchen that don't extend over the worktop, so that I can't bang my head on them because I keep leaving them open. Now I tend to leave the cupboards open because I don't notice the doors are there. The erm, what else have I done. I put a gate in at the top of the stairs to stop me falling down the stairs while I'm at the top of the landing. And that's proving very effective.

Simon's home seemed full of new dangers. Simon was most concerned about falling down the stairs. But he could adapt to these problems, by installing cupboard doors which didn't open as far, or putting a gate on his stairs to stop him falling (photograph 15). Tom struggled to carry objects up the stairs, so he made a rudimentary rope and pulley to take things to the first floor (photograph 16). Through talking about the home, men could demonstrate an instrumental approach to their illness; a problem solving nature concerned with finding solutions to their difficulties.

However changing the home also led to a further dilemma; PD and its associated problems meant the home could lose its existential meaning (Milligan 2003). David above spoke about his worries about having to leave the home, emotions which were complicated by the increasing difficulties he was facing;

> *GG* *And what are your feelings about the prospect of leaving here?*
>
> *David* *Dreadful, I don't want to. Because I've had thirty years, forty years here, of happy life, but if it's got to be done it's got to be done, that's the sort of person that I am.*

A pragmatic self, concerned with dealing with the problems David faced came into conflict with the emotional meanings attached to the home; as the place he had raised a family, and spent many years of married life. Changing the spatial layout of the home therefore raised further dilemmas, disrupting these emotional meanings. Simon changed his home to make it more practical for his needs, attaching a gate to the top of his stairs, and by installing a walk in 'wetroom'. But these changes could also reinforce the presence of his illness, leaving him facing a dilemma between adapting his home and ensuring it kept its home like nature;

> *Simon* *The obvious things in the bathroom I've had done, I've had it made into a disabled bathroom, but it doesn't really look like a disabled bathroom cos I haven't had the*

drop bars and grab handles put in, I've had spaces made for them to go in, so I've future proofed it, but I don't need to put them in now, and they've made the wall so strong. It's all a timber construction, the, behind the plasterboard there's an inch of plywood over the whole of the wall, so I can screw or bolt an object anywhere I want. And I've made the room with the space to put grab handles in where I need them. Erm, but that's standard stuff for disabled, being proactive in having it done when the bathroom was put in.

In designing his bathroom it was important that it didn't look too clinical, too 'disabled'. Home could become a 'disabled space' something Simon wanted to avoid. The changes made to the home could further reinforce a sense that he was different to his past life and the life of others; either as disabled or as prematurely old (Milligan 2005). Any changes to the home were therefore made in tension with this dilemma. As these meanings changed, a further tension was revealed; between their emotional attachment to the home and their thinking of the home as a pragmatic space. Bob and Tony and particularly David all spoke of an emotional connection to the home.

In PD, home also became a place where men increasingly had to enact their masculinity. Masculinity is most usually been defined away from the home; at work, on the sports field, or in the 'great outdoors', with home being thought of as a feminine space (Dupuis & Thorns 1996; Mowl *et al* 2000; Dyck & Dossa 2007). But as men became less able, the home space became more important as a place where they could show their continuing competence and mastery (Varley & Blasco 2000). In the past they achieved this through home maintenance, DIY or gardening. Now they were less able to do so in the present, but could still tell often lengthy stories about their previous achievements. Bob spoke in detail about the conservatory he built several years ago. Dafydd had installed the central heating system in his home. Now they couldn't do many of these tasks, but could speak about the smaller acts around the home or in the garden continuing to assert control over the home and over their lives.

Harold noted with some pride that since becoming a widower he had learned to look after himself, using this to show that despite his difficulties '*I get on quite well*';

> *Harold; Having said all that, I get on quite well. As you know I live on my own, and I cook for myself, I do my own housework; I do my own ironing, that sort of thing. Not that I like doing any of those, but needs must. as it were. (...) I've had to learn to live by myself, for a long time now, in some way it's probably been a good learning curve as it were, before all this happened I was used to being on my own.*

Areas of previously female competence could be spoken of in order to show men's continuing abilities. But to do so, housework couldn't simply be told as a routine act. Instead it was spoken of as an 'event'; an accomplishment and therefore a way of performing a pragmatic, competent masculinity (Calasanti 2010). Even if their abilities were declining, within the home men continue to show themselves as able, productive and active, transferring masculine responsibility into places assumed to hold traditionally female competence (Ribiero *et al* 2007; Calasanti & King 2007b). Indeed the importance of such narratives can be seen in their opposite; in Ian, who became tearful when talking about just how difficult housework had become. In sum, the home could be remade in its meanings, reinforcing a dynamic, problem solving and active masculine self within what was a shrinking lifeworld. But if men couldn't sustain their everyday acts within the home, its meanings could also become increasingly negative as mean struggled to cope with their routine activities, instead reinforcing the embodied and social consequences of their impairments.

Part 4. Re-negotiating meaning in men's family relationships

Most of the men found their positions within their families changing. Albert discussed how he felt about being cared for by his wife;

Photograph 17. Albert doing the washing up

Albert *I'm very grateful for what my wife does, I don't mean to say that some aspects of the situation being a cared for person is nice and it's not so nice on occasions. Cos you have a feeling of obligation err, you know you're not doing enough. Doesn't worry me too much because I do what I can when I can. Go and empty the bins as I did this morning. So you know that's saying thank you in a way. Saving her doing that particular job. And I don't like doing things in the morning because I'm able to do more, I've got more energy. If I had to do that last thing at night I'd say no thanks, its bad enough having to get up those stairs.*

The growing experience of being cared for meant Albert, along with several other men faced losing their patriarchal status as the head of the family. They needed to account for care in a way acceptable to their biographical sense of self as men (Ribiero *et al* 2007). Men did so in numerous ways. First, instead of talking about care, several men instead spoke of 'help';

Hugh *You can't beat (PD), you just have to accept help as err... people, very considerate, some people to be honest. Friends are very helpful. If you need help. And the choir, the driving, if I'm not up to it, then someone will take me everywhere, definitely, so... (...)I'm a bit like that to be honest. Independent, I've always been independent, but erm, and I try to be independent now and I shouldn't be really. No.*

Photograph 18. Albert with some flowers for his wife

Hugh had to acknowledge that he did need help; *'I try to be independent and I shouldn't be really'*. Independence was desired, but was increasingly unachievable. However care was also anathema to a masculine sense of self. To deal with this few men spoke directly of being cared for, instead they talked about help (Mishler 1984; Riessman 1993). Help was similar, but held different meanings to that of care. First, perpetuating traditional gender roles, cooking and cleaning were stereotypically subsumed within wives responsibility. But Hugh and Albert also showed that they 'helped', for example Albert helping with the 'washing up' (photograph 17). In addition, men also focused on their gendered responsibilities within the home; jobs like financial management, home maintenance or driving. By talking about help, men could show that not only did they receive help, they also gave it, by doing so contributing to the gendered production of the home, helping men to retain autonomy and authority even when many of their functional abilities declined. (Andersson & Sidenvall 2001; Calasanti & King 2007b).

Albert *Err, what else err, in regard to Parkinson's disease, she must do a lot of hard, physical graft for a person who does not always so gratitude or affection in the right way, or in the way she considers the right way. Yes I do buy her the odd bunch of flowers and the odd bar of chocolate, err, and just put them down as if, and you know, that's that. I don't make a fuss about it. And she appreciates that. I probably don't do it often enough.*

As PD progressed continuing to 'help' through household tasks became more difficult. But men could find other ways to reciprocate. If Albert couldn't repay help through his household acts then he could show gratitude through alternative means, for example the giving of gifts (photograph 18). It was important for Albert not to display too much emotion; *'I don't make a fuss about it'*. But by gift giving Albert found a way of repaying his wife's *'physical graft'*, a male appropriate way of showing emotional gratitude; avoiding any overtly emotional expression, but also in his mind repaying his wife for her care.

How men responded to care was also shaped by who was caring for them;

Tom *Well you're going to end up finishing in a home aren't you? Perhaps I should have had daughters.*

GG *what do you mean by that?*

Tom *Well if you had daughters, I think they're more, I don't know, they used to be more liable to look after they're parents. They had more of a bent, for nursing and looking after them. In my day daughters were expected to look after their parents, whereas the boys were nowhere. So I suppose that's part of heritage.*

Men attributed different meanings to care depending on who they felt was giving it. None of the men wanted to be cared for, but if care was necessary it was assumed, in Tom's case explicitly that wives and daughters would provide care as part of their gendered family responsibilities. Instrumental care from daughters was easier to

accept than from sons, daughters were either assumed to be more caring, or that it was expected of them as women; *'in my day daughters were expected to look after their parents'*. In contrast son's, although in a few cases actively involved in care were largely absent from men's narratives of care. Sons did provide a form of care, yet this wasn't usually recognised as care. Instead men talked about a social companionship with their sons based around practical acts; going for a 'beer', to the football or to *'watch the telly'*;

> *Ian Well I go to me son's once a week, Thursday night, dinner. He lives on his own, he's divorced, and err, he's going through a rough patch with his job at the moment (...) so I don't push him for anything. See him once a week, and he cooks me dinner for me. We sit down and watch the telly.*

Sons kept an eye on their fathers, looking after their interests and making sure they were alright. But they rarely intervened at the level of the body and its instrumental acts, helping men to dress or wash. The interest of son's was easier to accept, seen as less controlling and more advisory. In contrast Simon explicitly spoke about what he saw as his daughters attempts, albeit well-meaning to control his actions. They were therefore to be resisted;

> *Simon. My younger daughter worries about me, and she'll say dad phone me when you get home and stuff like that, and I don't. Because I won't allow myself to be in a situation where (2) because the kids are worried about me I have to check in. I don't, and there's two reasons for that. One, I don't like being in that controlled situation. If I always phoned in when I got home, erm, and I didn't one day, then the cavalry would be out. So (2) I phone when it's convenient to phone, but they still say to me phone when you get home. And sometimes I will phone, but I don't make a habit of it, because I don't want them to put themselves in the worry position where they always worry about dad*

'The kids' was Simon's daughter. Any such interest from his son was likely to be spoken of differently. How men negotiated and responded to the receipt of care was therefore profoundly gendered. Meanings of care were associated with instrumental, feminine tasks, what Twigg (2000) calls 'bodywork'. Men could be grateful for this assistance, but also had to resist it in some form. In contrast emotionally attuned care could be thought of as social companionship, becoming more acceptable when judged through male appropriate forms; through acts of doing with, rather than talking about (Coates 2003). Men therefore engaged with gendered language and gendered meanings when talking about care, prioritising emotional yet masculine forms of care over the 'bodywork' provided by wives and daughters (Twigg 2000).

In summary to be 'cared for' could have particularly pernicious effects on men's sense of self, eroding a masculine autonomy experienced through the most taken for granted acts. Care was equated both with burden and with obligation. But care could be negotiated in order to derive different meanings. By speaking of care as 'help', viewed either as a reciprocal arrangement, or as a 'gift' a coherent male self could be preserved. Furthermore, by subsuming instrumental care within expectations of female roles intimate, instrumental forms of care could be more easily accepted, marginalised when compared to the meanings of 'care' received by men. However where possible men also had to resist these acts where possible, showing their independence and authority. Through talking about care in this way men could maintain an authoritative position in their family relationships while avoiding the meanings of dependency associated with formal care (Varley & Blasco 2000; Ribiero *et al* 2007; Calasanti & King 2007b).

Part 5. Dealing with a changing social presence

Finally, men also experienced profound changes in their wider social relationships. The body's new found being-for-the-other could become deeply shaming; breaking social norms relating to our everyday embodiment (Nijhof 1995; Svenaeus 2009; 2011). Men therefore needed methods to deal with the potentially stigmatising presence of their bodies. Simon described how he dealt with a body 'showing up' to others;

> *Simon I mean in Welsh class not long ago, all the people in the class know I've got Parkinson's, and I was sitting at the desk and I suddenly noticed the desk was sort of (imitates shaking) doing that. Well there was a woman sitting at the other end of the desk who came in half way through the class, for the first lesson she'd been to. She didn't know what was wrong, she looked really odd at the desk, and she saw me shaking and I could tell she was saying 'what's up with him', well the other girl sitting next to me, she knew exactly what was wrong, she grabbed the desk and stopped it. And seeing her do that was enough for me to realise that I was doing it. And I stopped, and I explained to her afterwards that I had Parkinson's and that allayed all her fears. I hadn't had the opportunity to talk to her. So being up front in, and getting it out of the way is a strategy for coping with it.*

Simon suddenly became aware of his being-for-the-other; how his body looked to others in the class. But Simon also describes how he could deal with this experience; in his case by *'being up front'*. Being up front involves being open and honest, telling others about his condition and not trying to hide it. For Simon being up front served a number of purposes. First sharing his diagnosis disarms other people, *'allaying their fears'* by showing that he is not 'peculiar', 'deviant' or 'weird'. By stating that he is 'ill' Simon provides an acceptable reason for his strange movements. Second, Simon is being honest and straightforward, to others and to himself. He is not expending extra effort engaging in subterfuge, trying to hide his symptoms or deceive those around him; something both Roger and John tried to do. Finally, Simon also emphasises that

his errant body movements are not 'him', further dissociating them from his core sense of self. By being up front with others, he can show that he is not defined by his PD.

Several men chose to approach the social appearance of their PD by 'being up front'. However it was important that this was seen by others in the 'right way'. Humour was a useful means to be up front, showing others that they didn't let the disease 'get them down' (Solimeo 2009). Henry had several anecdotes which could be used to make light of his illness;

> *Henry Humour is what I find is one of the best weapons if you've got Parkinson's. Erm, I was at a golden wedding about three or four years ago, erm, not a big do, but a smallish do, probably about twenty or thirty people there I suppose, and we were all sitting around waiting for the trifle to be served, which everybody was having as their next course. Myself, with the tremors in my hands, and another chappy, he had a terrible shake in his head, his head lolling around, and you could see people were embarrassed looking at him or looking at me rattling the plates and that you know. So I thought this won't do, and the fella, his name was (friend), and I said hey (friend) is it trifle next, and he said yes, and I said well let me and (other friend) serve it, we'll get it spread around a lot quicker that your waiter. And they absolutely burst out in laughter and everybody was happy to be with us and talking with us. We came into the community rather than being outside it, you know. So that sort of position, I've had it many a time, many a time.*

Henry, Dafydd and Tony spoke of their symptoms in a humorous, self-deprecating fashion, calling their symptoms the *'Chinese Shuffle'*, *'just the Parkies'*, or *'the shakes'*. Dafydd nicknamed his local support group *'the shakers club'*. *'Laughing about it'* was an important means of dealing with PD publicly, showing others that they didn't take themselves or their bodies too seriously and that their illness was something that they could 'talk about'. By using humour in this way, Henry could show others that he was dealing with PD in a socially acceptable way, enacting a public self which tried to minimise any anxieties that others might feel about their condition.

However not all the men could be so open to others about their symptoms. Roger told me about a hospital admission following a car accident, during which he began experiencing frightening hallucinations;

> *Roger* *Yeah that time was frightening, you can't convey to anybody, it was absolutely frightening, and so real it was surreal, and so real you know. And, oh my god. (3) Yes. Phew, I told you everything you'd think I'd lost it you know. Its something I want to keep in the dark, its, I don't want to go through that again.*
>
> *GG.* *No, no, no that's fine. Too difficult to deal with?*
>
> *Roger* *Yeah, it was frightening. I don't frighten easy, as I think you know. But err, when your mind is doing stuff like mine was, and that's got to be down to the drugs, or lack of them. Its like a forced detox wasn't it. When I tell you anything, you'll be forced to write that book. Terry Pratchett will have nothing on what I tell you, you know.*

Making jokes about their bodies, finding ways of hiding symptoms, or explaining their various predicaments could only go so far. Symptoms like incontinence or hallucinations could too distressing or stigmatising to easily talk about, even to 'experts'; challenging men's self-concept; '*I don't frighten easy, as I think you know. But...*' In this case hallucinations threatened to make Roger seem to 'lose his mind'. When experiences had such an effect on men's sense of self, they couldn't easily be shared with others. Roger felt unable to talk openly about such experiences, to his family or to his health professionals. Some symptoms could be too severe, too stigmatising or even too alien for others to understand. Hugh struggled to explain to me just what an off period was like, or Roger who felt unable to describe his hallucinations on tape (it was only after I switched the recorder off that he told me about his hallucinations). Tony experienced an anxiety so acute that it led to physiological effects; either panic attacks or the worsening of PD's symptomology.

Photograph 19. Hugh and his local male voice choir (Hugh is in the back row, 2nd left).

Many symptoms broke social expectations of bodies, and in particularly of male bodies in such a way that men couldn't easily share them with others. 'Being up front' although seen as an ideal approach to dealing with PD therefore couldn't assist in all men's bodily experiences. Given the intensity of such experiences, it is perhaps unsurprising that many men found it was easier to curtail their social lives. Previously a member of a large national choir, Hugh now sung in a smaller, more local choir;

> *Hugh I used to be a member of the choir, and err, it affects you completely. I was a good singer, and err, I noticed on the film, being filmed, the choir, and I was all shaky, so I decided to give the main choir a miss. I still sing with the local choir in (home town), but I miss the main choir, competing all over the world, everywhere, so that's something I have to do without. The local choir when I'm up to it, yeah.*

First men tried to find ways to manage a social withdrawal, reducing their involvement while maintaining a story that they still had a viable social life. They still went out but not as much, and to less stressful places. Others found alterative sports to take part in. John was considering taking up less physically demanding activities; bowls instead of

golf. Other curtailed their involvement; instead of heading into the mountains with his walking group David now stuck to easier, lowland walks. Hugh now limited his social life to family or close friends, only socialising in small, local pubs with close friends and doing this only infrequently. Through these acts a declining social life could be at least managed. But some found social activities were being taken from them. The anxiety of public places meant Roger now avoided anywhere with '*lots of people*';

> *Roger Going into a café to sit down, I'll walk in like nothing's wrong with me, if I sit down, and then try to get up again, oh, you know. It hits you. So if we go out for a meal we try and go out early, before lots of people come out. That's a real, real problem I have. But you just plod on.*
>
> *GG. And is that just around strangers, or is it around friends as well.*
>
> *Roger. It doesn't matter really, erm, whether it be a crowd of strangers or people you know. I mean I was at a party, I think it was two years ago, my mum was eighty five or something. And err, I had a, a few drinks were here, and people were around there. And I found it so hard to circulate, to the point where I ended up sat there, mixing the fruit drink, punch and fucking drinking most of it myself, I felt so, I felt so obvious, you know. But my wife was having to do the circulation. And I, I am a party animal believe it or not. And I was having a problem. So I was sat there, drinking and drugs doesn't mix. I just couldn't (2) if you've have put a gun to my back I couldn't have walked in there, into the lounge with other people. The more I did it, it was becoming a bigger and bigger mountain to climb.*

Tony also had a similar experience, facing an acute challenge to their biographical sense of self as they struggled with their social encounters. In a common expression, Roger felt much more 'obvious', a felt stigma in which he seemed to be highly visible to those around him. Roger, a previously gregarious individual tried to 'put up a front', to hide his private self behind a public persona. But doing so could lead to often acute anxiety as he struggled to achieve it. He was therefore caught in a further tension. He

wanted to socialise; to be around other men or to go on holidays. But when he did he increasingly couldn't cope. He had little alternative but to scale back his social life, staying at home more and more, increasingly feeling isolated and alone. If most men tried to 'be up front, Roger found he was having more and more to hide away, an experience growing worse as his PD progressed.

In summary, all of the men experienced a changing social presence in the world, intimately tied up with the public display and public performance of their bodies. Men could find ways of managing this display, most often by 'being up front'. Although some spoke of hiding their illness these were in the minority; PD was in most cases so visible it couldn't be hidden; forcing men to account for their illness. Most men could account for PD in this way, at least for a time. But as it progressed others found themselves having to slowly withdraw from a social presence within the lifeworld, with the potential to leave them feeling increasingly isolated. Through both accounts, men could therefore find ways of describing their changing involvement in the wider lifeworld, showing how they continued to maintain a social presence or if necessary, managing its slow decline, or when needed, trying to explain their withdrawal from the world.

Conclusion

In this chapter I have been concerned with how men cope with PD. But rather than engaging with the models of coping common throughout much of the psychological literature and in the literature on PD, I have instead been concerned with the phenomenological question of what it means to cope; how men, through their everyday acts; accomplish coping within the lifeworld. The world now felt like a very different place, possessing sparks of familiarity, but also requiring whole new ways of

interacting with its various objects and people. But by telling stories about how they coped and the various acts they used to do so, men gained the opportunity to re-structure these narratives.

Much of the literature on PD's subjective experience has focused on how men seek to maintain a sense of continuity with their past lives (e.g. Habermann 1999; Whitney 2004; Phillips 2006). Such findings are reinforced in my study, in which men sought to maintain continuity with a biographical sense of self, doing so by telling stories about the many activities they continued to take part in, and the many duties they continued to fulfil. However, although men tried to maintain a continuous self, using their activities in order to do so, the meanings imbued in these activities had to change. Central to these new meanings was men's changing embodiment. The body came to possess new meanings; a present to hand experience in which the body had to be managed and cajoled (Toombs 2002). Men could also learn how to negotiate this changing embodiment by seeking information about PD, using it to understand their condition and its effects. Men could also try to change their body's ability to negotiate the home, doing so in ways that could change its everyday meanings. Men could also talk of their changing family relationships, doing so in such a way that they could make positive meaning in the face of the growing experience of care (Fine & Glendinning 2005). Finally, men could also find ways to deal with the changing social presence of their bodies, choosing to be up front, or finding themselves hiding away.

In PD, coping has been predominantly addressed from psychological models allied with approaches to the question of quality of life. The stories people with PD tell of coping, and the meanings derived from coping have only rarely been considered. This thesis illustrates that the lived reality of coping is more complicated than demonstrated within many of the existing coping models in PD. Most of the work in PD has shown

that an adaptive, problem solving approach to coping is most successful in PD, while emotional or avoidant forms of coping are considered 'maladaptive' (Montel *et al* 2009; Hurt *et al* 2011). This study shows similar findings, but also shows both how men try to enact adaptive forms of coping, and the complexities of doing so within men's own individual lived realities. Not least men's stories of coping and the approaches they illustrate are never static. As the body in PD was continually in flux, both on a day to day level and through PD's progressive nature, so men's approaches to coping also had to change. Men could be coping at one point in time, but soon find their coping strategies beginning to deteriorate, often very quickly. In my last contact with Dafydd for PROMS-PD he told me a very different story than the one he told in the interviews explored here, one where he was now struggling to cope as the repertoire of coping strategies he had built over many years were slowly beginning to fail. As Habermann (1999) notes, how men with PD coped with their illness evolved through men's individual contexts; the meanings, acts and concerns intelligible to them in addition to their individual symptoms and their contextual effects on men's lifeworlds. It is not as simple as to say that men could 'choose' how to cope according to what methods appear to 'work' best, as identified within the coping literature. Nor did 'coping' remain the same. Rather coping in PD is a contextual activity rooted within individual meanings, changing according to individual circumstances. In order for clinical services therefore to help men with PD to cope, it is crucial that we understand this process and find ways to deal with these contextual meanings; how men mobilise coping through their acts, how they revisit coping as PD worsens, and what this experience means for their lifeworlds.

Chapter 8. PD and an ageing masculinity

Introduction.

So far ageing and masculinity have been in the background of my account of PD. In this final chapter I bring this issue to the foreground, to explore how the stories men told about their PD were influenced by gender and ageing (Arber *et al* 2003; Calasanti 2004; 2010). A growing number of studies have conceptualised masculinity as a relational practice, differentially affecting men's positions in the world *as men* (e.g. Connell 1995; Watson 2000; Emslie *et al* 2006; Robertson 2006b; 2007; O'Brien *et al* 2007; Robertson *et al* 2010). Although retaining power relative to women, men occupy differing positions of privilege in the world according to their individual and social characteristic; for example whether they are gay, poor, or indeed old. However this approach has only rarely been applied to the study of older men, a situation which has only recently begun to change (Arber *et al* 2003; Calasanti 2004; 2010; Meadows & Davidson 2006; Thompson 2008; Solimeo 2008). By engaging with an ageing masculinity, we examine how being ill with PD shapes how men see themselves *as men,* for example as ageing men or as ill men (Calasanti 2010).

The specific role gender plays in the PD experience has seen little study, while study of its gendered effects on and men's lives has been almost non-existent (Solimeo 2008). Given PD's gender prevalence as an illness predominantly affecting men this is a key gap (Haaxma *et al* 2007).Some attention has been paid to sex; the demographic or biological differences between men and women with PD. A few studies have examined women's experiences of PD, usually through stereotypically feminine activities such as cooking or shopping or its biological effects on 'womanhood' (Posen *et al* 2000; Andersson & Sidenvall 2001; Schartau *et al* 2003; Fleming *et al* 2004). In contrast

studies of PD in men have almost entirely focused on erectile dysfunction (Meco *et al* 2008). Within these studies the issue of gender has been neglected. So far only Solimeo (2008) has either examined men, or more significantly shown how a relational approach to gender can expand our knowledge of PD's experience. Solimeo illustrates how judgements about QoL in PD differ according to gender. Women described issues with their interpersonal relationships. In contrast men worried about the appearance of their bodies, challenging an instrumental, pragmatic and fundamentally masculine embodiment (Robertson *et al* 2010; Calasanti 2010). Solimeo only considers a few elements of gender's impact on PD, ignoring wider aspects such as the role gender plays in men's everyday activities or how they respond to PD's symptoms. There is therefore further scope to examine PD's gendered experience and particularly how gender relations shape men's judgements about what PD 'is'.

In this chapter I build on Solimeo's earlier work to explore how PD's lived experience is explicitly gendered; when men talk about PD, they simultaneously talk about both masculinity and ageing. Central to this chapter, I explore the performative nature of gender; masculinity is not something men are, rather it is something they 'do' (Butler 1990; Laz 2003). When men describe their activities; they are 'doing gender'; positioning themselves within the world according to powerful expectations about what men are and how they should act. But by affecting men's ability to perform and accomplish gender, PD comes to the foreground of men's lifeworlds; becoming something which alongside the body and time, must be brought into awareness. But this experience is also filtered by age; men's judgements being made not simply based on their position in the world as men, but also as older men. I therefore discuss two key questions. First in part one I examine how PD's various symptoms are thought of as a threat to masculinity, eroding men's status in the world as men. In part two I pay

attention to a wider issue, the role masculinity plays in how men understand and respond to PD. I argue that an ageing form of masculinity gives men a resource through which they could know PD and its effects; showing how they respond to their illness according to masculine ideals within age appropriate forms (Spector-Mersel 2006; Meadows & Davidson 2006). Finally I conclude by discussing PD's experience in relation to Connell's (1995) seminal concept of hegemonic masculinity. By examining how men with PD negotiate and where necessary re-appropriate hegemonic ideals within their own lifeworlds, we can see how men make meaning from their condition, drawing on masculinity and age together in order to do so (Emslie *et al* 2006; Calasanti 2010).

Part 1. PD's consequences for masculinity

Featuring most frequently in men's direct talk of masculinity, men spoke about PD as a threat to their masculinity; to the active continuation of a masculine self. Drawing on the work on an embodied masculinity first described by Watson (2000) and built upon by Robertson (2006; 2007; Robertson *et al* 2010), I now discuss how men thought of PD as a challenge to their masculine status through three embodied areas; a pragmatic embodiment concerned with men's everyday tasks; a visceral embodiment experienced through a changing physical body, and an experiential embodiment relating to men's changing experience of the world *as men*. Through these accounts, we see how men experience masculinity through their acts and accomplishments; PD having men's ability to accomplish what they saw as masculine acts and masculine responsibilities.

PD's threats to a pragmatic masculine embodiment; Loss of strength and power

When men spoke about their PD, a number of words, phrases and metaphors occurred repeatedly; *'Everything's getting harder', 'I'm slowing down', I'm losing strength'. I'm not as strong as I used to be', 'Losing power', 'lacking energy', 'I can't do heavy work'.* All these terms reveal how men made sense of a changing body. But importantly, these descriptions are all heavily gendered. Not simply the consequence of changing bodily abilities and changing sensations, men's descriptions of the physical body were profoundly gendered, shaped by men's expectations about what they should be able to accomplish. Through changing men's physical abilities, PD challenges a pragmatic embodiment, concerned with men's abilities to accomplish these tasks. In this section I therefore explore how through their accounts of a changing pragmatic embodiment men spoke about a changing physical body, now struggling to accomplish its tasks (Watson 2000; Robertson 2006b).

I focus on two linked descriptions featuring across many of the men's accounts; the loss of physical strength and growing sense of physical weakness, to show how these two accounts are explicitly gendered. Roger described 'weakness' as one of the core problems of his PD;

> *GG How did the disease progress?*
>
> *Roger. Well it was to do with weakness, erm (2) this is my main driving hand, a lot to do with weakness, started there, and went down there, and then somehow its coming up here now (demonstrates going downright side of body, then up the left side). (...) Enough of that, carry on. (...) (When walking) I was generally weaker, using two sticks more often than not, I mean at this minute in time I'm using one stick, I was hardly ever was I. I'll leave the other one outside, have a rest. Yeah, just this prevailing feeling of err, lack of power, you know, mental and physical.*

Roger along with many other men spoke about the loss of physical strength. This loss is also associated with the loss of *'power'*, and of a growing sense of *'weakness, being weak'*. All of these terms possessed a symbolic, gendered significance; associated with the loss of mobility, of capability, of autonomy and of activity, all ideals of an active male that he now struggled to meet. Fatigue was also closely associated with the loss of strength. Anything requiring exertion left them tired, but this was no longer the result of a job well done, of a busy, productive day. Instead it had new meanings, as if all Roger's strength simply left him; he had been drained of all his energy. Men's sense of weakness was defined as the loss of its opposite; strength, a bodily capability PD threatened to strip away. At its core, to be the successful embodiment of a man is to be fit, strong and active. By making Roger 'weak', PD challenged his ability to meet these masculine ideals.

Importantly, for most loss of strength was not simply a physiological experience. It was experienced through the loss of instrumental abilities; not least by making what Tony called *'heavy work'* more and more difficult;

> *Tony: Err, just, I haven't the energy to do sort of, you know heavy work, or stuff. I can only, I can only do things like, if there's digging I can only do it for about half an hour and then (...) And then I come in and I do whatever I'm doing, have a read or whatever, and if I feel like it I go out and do a bit more. But erm, I don't, I mean I've got that Land Rover and that's, bits drop off that regularly, as they do, and I've managed, I've managed to do quite, some quite heavy things with it but, you know, once I get going, I'm not too bad, but it depends on, on the day (...)*

Photograph 20. An example of Simon's intricate model making

Heavy work was also directly linked to masculine ideals of physical strength; lifting and carrying, operating machinery, building or making things. But it is also linked to productivity and labour; the idea that men can be physically productive; to make and do things. Making and doing; either in the form of physically intensive work or alternatively skilled, technical work was fundamental to almost all the men's social activities; from sport to gardening to model making (photograph 21). But PD now constrained their ability to 'do' these kinds of work. Heavy work could not just be done; they now lacked the sufficient strength. Instead they had to take their time, taking frequent rests. Skilful work also became difficult as they lost fine, dextrous control over their hands. Things couldn't be done as easily, while some couldn't be done at all. Through losing these abilities, either 'heavy' or fine technical work, men faced the loss of key masculine abilities predicated on a physical strength or technical competence, each defined through men's activities.

In summary, men's changing physical abilities led to a loss of physical strength and growing weakness, two key problems which directly challenged masculine ideals of a

physical embodiment. But these ideals were understood through a changing pragmatic embodiment. For most, loss of strength was located in their experience of their everyday activities. They became weak not because they couldn't just lift heavy weight or fulfil various acts of strength. Rather weakness meant they could no longer *work*, engage in the various productive labours a masculine embodiment was built around. If masculinity is something men indeed do, then it is done through various activities, including physical labour and technical work. By either making them extremely tired or by getting in the way of their skilled abilities; PD prevented them from meeting the ideals of a pragmatic masculine embodiment based around physical strength and technical skill. Through these losses men faced the gradual erosion of a masculine self.

PD and the erosion of a visceral embodiment; Incontinence and sexuality

Many of PD's physiological symptoms were experienced through their consequences for men's acts. But men also had to deal with a changing visceral, physical body (Leder 1990; Watson 2000). Suddenly several men found themselves attending to what were once deeply hidden bodily processes; the movements of the bowel, or neurochemical impulses occurring deep within the brain. These manifested themselves through a number of functions; breathing, swallowing, drooling, smelling, touching. Two intimate bodily processes featured most prominently; incontinence and sex, doing so because they directly threatened an embodied masculine self (Tepper 1999; Chapple & Ziebland 2002). By exploring how men spoke about incontinence and sexual function, we see a body which challenges deeply held views about a masculine, visceral embodiment; in which men should fundamentally be in control of their own bodies.

Almost all the men faced problems with bowel movements. Constipation was commonplace. But more distressing, and harder to talk about was its opposite;

incontinence. Henry described an episode of urinary incontinence happening far from home;

Henry *I suppose one story I can tell you which is related to the car dealing, and to the pressures involved, I was looking for a people carrier, and there was one advertised, so I jumped into the Honda and off I go to the Wirral, horrendous journey, the weather was terrible (...) I went to get out of the car and I was soaking wet. Absolutely soaking wet, my bladder had let loose. Completely, and this was before I was wearing a leg bag you see. So now I'm in a position now I'm about fifteen minutes late for an appointment, I'm soaking wet, I'm a long way from home, I'm fed up, so do I go home or what. So I rang them and the fella answered who I'd been trying to deal with, and I said, look I'll tell you straight now, I've got Parkinson's disease, I've just had a mishap in as much as my bladder's just let go, I'm soaking wet, if you don't want to see me I quite understand, but I can't come back all this way again, so its now or never sort of thing. So I did it, I walked in there soaking wet, plush carpets which I went round for obvious reasons, and they offered me to sit on a three piece, I said no way. So we did the deal, and I can honestly say coming away from there they were very friendly people, they, a lot of them were saying, (inaudible) there were three men there that I was dealing with, two of them had got experience of Parkinson's in the family, and they wanted to know more, and I spent more time discussing my Parkinson's than I did doing the deal, so, but that sort of thing has happened to me, not to the extreme as that, but err, more than once*

Roger also described his growing problems with continence;

GG. *What are the problems that (PD)'s causing you at the moment.*

Roger. *Erm, getting to the toilet in time. You know, it's a simple thing but its, it erodes your masculinity a little bit doesn't it. You know. So why I wear white trousers I dunno. Simple things like that, if you happen to be weak, it takes a hell of a lot of bladder control. I can just about make it, but sometimes you fail. It doesn't do anything for your masculinity does it.*

These intimate bodily acts, largely unacceptable to talk about in conversation beyond humour (e.g. fart jokes) suddenly become acute problems. 'Shaking' could be humorous; *'just the parkies'*. But incontinence couldn't be joked about. Indeed even talking about these intimate functions could transgress important social boundaries (Chapple & Ziebland 2002). Incontinence threatened to expose the body publicly in a way much harder to explain to others, something men couldn't just joke about. Suddenly men had to be continually conscious of the movements of their bowels, or their urge to urinate; limiting where they could go to places with easy access to toilets. But more so, it threatened their masculine status as they could increasingly fail to control the body, with potentially humiliating public consequences. In the body in PD could potentially become so out of control that it ceased to be both an absent and silent presence; at odds with a masculine visceral body as a silent presence (Shilling 1993; Chapple & Ziebland 2002; Kelly 2009).

A second domain of intimate bodily experiences was sexuality and sexual desire (Meco *et al* 2008). Alongside incontinence sexuality in PD is also a complex experience, shaped by expectations based around masculinity and also around age (Bronner 2011). Most found themselves either experiencing a reduced sexual desire or struggling with erectile dysfunction (Meco *et al* 2008). But most assumed this to be the 'natural' consequence of old age, reproducing social expectations of older men as asexual beings (Calasanti & King 2005; Solimeo 2009). When older men spoke about sex, they used a range of ageing stereotypes; *'I'm a bit old for that now'*, *'I'm a bit long in the tooth for that sort of thing'*, *'that's long past'*, *'I don't bother about that now'*. A sexual biographical self was part of who they were, but had faded into memory. It could be argued that ageist social perceptions that older people are supposed to be asexual beings had been largely internalised by the men; thought of as a natural part of older

age and therefore no longer part of their lives. By doing so, the sexual problems of PD were easier to accept, indeed were seen as an irrelevance.

An alternative interpretation is also possible, one which considers gender as relational. Men sought to negotiate a contradictory element of an ageing masculinity; that as older *men* they should be interested in sex, but as *older* men they shouldn't be. (Calasanti & King 2005; 2007a). Albert's account shows up the problematic nature of sex, sexuality and a masculine old age.

GG *And last time I saw you, you mentioned that you'd been viewing pornography.*

Albert *Yeah. I mean is there any man who doesn't occasionally. I don't anymore because it's rather boring.*

GG *Was that relatively recently?*

Albert *It's a substitute for the actual thing isn't it.*

GG *Is it relatively recently you were doing that?*

Albert *Yes I used to be scornful of it; it's an old man's hobby isn't it.*

For the first time in his life, Albert had begun to view pornography. Even in this brief conversation Albert speaks of sex in several contradictory ways; as a normal expression of masculinity; *'is there any man who doesn't occasionally'*; an age based deviance; *'its an old man's hobby'* or a medical problem; a further example of impulse control disorder (Wu *et al* 2009). Sexual desire therefore remained a core expression of masculinity, even if older men felt it was no longer appropriate to them. But those that did experience continuing sexual desire in older age found themselves questioning what was normal, what was unusual, what was deviant, even what was pathological. Sexuality and sexual function therefore occupies a problematic position, how men

negotiated difficulties with sexual function in PD being rooted in wider potentially contradictory meanings about how men, and how older men such act (Calasanti & King 2005; 2007a; Bronner 2011).

Those men in middle age, in their 50's and early 60's had very different expectations about their sexuality. For these, the problematic nature of sexual function in PD was much more clearly felt. Roger had recently re-married and wanted an active sex life, But now he struggled to 'perform';

> *GG. Okay, and if you don't mind, how does (PD) affect your relationship with your wife?*
>
> *Roger. She's brilliant. well she just fills in the little blanks on everything, where I can't go out, or things I can't do, she's come to know me now, and its so, I want to make sure she's safe, you know, financially. Erm, I suppose from the sex point of view I suppose, I find that you're losing, what's the word, libido is it. Losing a little bit of that. It bothers me from time to time when I want sex. I don't dwell over it, I think she's satisfied, well I am. But I don't know. Yeah. I think we're happy.*

PD could challenge a sensual, sexual self. Roger was losing his '*libido*'. Suffering from erectile dysfunction he struggled with the act of intercourse. But more important to his sense of self Roger questioned whether he could 'satisfy' his wife; '*I think she's satisfied*'. His sexual function was not just about his own pleasure. In a further example of being-for-the-other, now Roger was forced to question himself in relation to the most intimate acts; challenging a central element of Roger's masculinity; his ability to sexually satisfy his wife. In losing his own pleasure, Roger couldn't meet his own desires, but also questioned his ability to give pleasure to his wife; and therefore his masculine status.

Sexuality is about more than sexual function; it is also about men's place in the world as sexual beings, a further embodied dimension challenged by PD. Newly widowed but only 53, Simon hoped to meet another partner in the future;

> *Simon Erm, obviously, I lost my wife in July, erm, but I would like to at some point, meet another partner. I'd like to think that if I've got another twenty years on this planet I don't want to do it alone. (...) Erm, but owning up to Parkinson's is going to be the kiss of death to any relationship. I question whether I'm actually erm, what the word; well I suppose tarnished goods is probably the best expression. Damaged property. You know does one want to take somebody on who's facing them because of all the difficulties it's going to entail. You know, it'll scare people off. (...) The other side to that coin is that I'm aware that I want to have another partner at some point, erm, I know it's a thing that I discussed with my wife, and she was adamant that I should, so I don't feel guilty for thinking about it, but when it comes to practically putting it into place its actually difficult to do it. Set against the fact that I'm aware that that storm is brewing, and it won't be possible once the storm has overcome me. Do you see what I'm getting at? I see the window of opportunity shrinking in front of me.*

Sexual attractiveness was the only dimension in which men noted the aesthetic, rather than functional appearance of their bodies. Simon avoided constructing himself as a widower; rather he was newly single, a sexual identity Bennett (2007) shows to be more acceptable to men. But PD also meant Simon was now *'damaged property'*, facing a shrinking *'window of opportunity'*. PD made Simon question whether he would be able to continue with a viable sexual identity; again making Simon prematurely 'old' as he was forced to consider that his life as a sexual being could be over. PD therefore didn't just emasculate men through the body's functional abilities, but through their ability to see themselves as fundamentally sexual beings.

In summary, PD meant that many of the core dimensions of a visceral embodiment suddenly became problematic, changing a masculine sense of self. Incontinence and

sexual function were but two experiences in which the body ceased to be absent and ceased to be silent. But unlike several other changing bodily abilities, they also featured so prominently in men's accounts because of their consequences for an embodied, visceral but also relational masculinity. Incontinence was about a body out of control, while sexual function was about the loss of intimate bodily competencies; transforming their presence in the world as sexual beings (Shildrick 1997; Chapple & Ziebland 2002). But this is complicated by social expectations of sex in old age; that although sexuality is key to masculine identity, it is a taboo in older age (Calasanti & King 2005; 2007a). As a result PD's visceral experience, in particular through incontinence and sexual dysfunction, could further emasculate men with PD (Spector-Mersel 2006).

PD and an experiential embodiment; Masculinity and its performance

Finally, I consider PD's consequences for what Watson (2000) describes as an experiential masculine embodiment; how men feel, and the role of their various activities in constituting their emotions (Watson 2000). Men experience emotion through their activities, giving meaning to activities as they enjoy, dislike or fear them, and to their bodies as somatic experiences are made sense of within the context of these activities. These activities are not simply an expression of emotion, rather they constitute men's emotional experience, and therefore their experiential embodiment (Robertson 2006b). As noted above, PD affected a pragmatic embodiment by affecting men's ability to accomplish their everyday tasks; activities like cooking, cleaning, driving. In addition sexuality and continence, both parts of a visceral embodiment also became problematic. All these, and PD's wider effects had consequences for men's ability to achieve an experiential embodiment; how they felt about their bodies, and about their status as men (Robertson 2006b; Robertson *et al* 2010). Deeply held but

unconscious attitudes around what men are and how men should be all became problematic as men found themselves struggling to meet these ideals, stripping away their masculine status and fundamentally making them feel differently about their bodies and their lives. When men can no longer do gender in a taken for granted manner, men's masculinity came to be questioned.

To explore PD's consequences for an experiential embodiment and its subsequent effects on how men felt about themselves, I focus on a single case study; that of Roger. Roger exemplified the problem of continuing to 'do' gender in PD, and its consequences for how he felt about his body, and how it constituted his presence in the world as a man. Roger thought of himself as a stereotypical 'bloke'; strong, loud, gregarious, bombastic, funny, but also possessing an aggressive, even potentially violent edge. However PD left Roger feeling *'half the man I was';*

> *Roger I'm trying to build up a little team around me of people I can relax with, you know. Because when you are on a building site, you can imagine you can have some right characters, they can be bad characters as well, you know. So I'm trying to develop a way of supervising without, you know without being there all the time, without causing stress. It's going to be difficult.*
>
> *GG. And that's frightening?*
>
> *Roger. It is. In the old days these sort of problems, fucking hell I can deal with that Wednesday afternoon, no problem. I'm so conscious of that, that I'm half the man I was. That's not nice.*

Roger feelings about masculinity was rooted in a 'macho' working class masculine identity organised around the workplace, around hierarchy, and around physical forms of strength, power and authority and its maintenance through aggression. Work gave Roger the opportunity to spend time with other men, but also to show his authority; as

the boss, as *'no pushover'*. However sustaining this workplace based authoritative masculinity; the 'boss', *'ordering people around'* became harder and harder. Increasingly Roger found himself having to put up *'a front'*;

> *Roger. It is, it's a front I have to put up, erm, it's a real front because, you know, if people think you are weak they'll take advantage of you. That's what I've found (...) you know it would be nice to be able to go any time you like, rather than having to psych yourself up or something, yeah.*

As Roger struggled to meet them, the social acts Roger's sense of masculinity was dependent upon were increasingly brought into relief. Instead of just doing, now Roger found himself having to act around other men in wholly new ways; *'having to psych yourself up'*. Masculinity had to become a conscious performance, something that no longer seemed to come naturally. Roger's conscious performance of masculine was most dramatically revealed in the following story, focused on his potential for physical violence, and the need to be a protector;

> *GG. You've mentioned about how the Parkinson's is affecting your masculinity. Can you tell me a little bit more about that at all?*
>
> *Roger. Well when you are in, say, in a situation with people say. I worry that I couldn't protect her (wife), because not, I mean I've had a guy come in there, with a chainsaw, you know. And err, I talked him out of it. And err, I was shaking like a leaf. When I said to him, don't think I'm scared of you, it's the Parkinson's. Got my axe out of the drawer, and he went. He frightened the shit out of me. And I could barely, but I said to him, well you know, you might think I'm scared, but its because I've got Parkinson's. Now where do you want the fucking axe, in your face or in your arse you know. But that ability to, I mean he could have hit me over with a feather, that's the truth of it, and that's why I question my masculinity when you are not able to defend your woman. Let alone yourself.*

There was more going on here than Roger told me. But what this showed was that Roger felt he could no longer meet the ideals of an aggressive 'macho' self. In eroding his physical stature, in slowing him down and in making him 'weak', PD removed the embodied platform upon which he had built an authoritative masculine self. All this had consequences for Roger's experiential embodiment as it forced him to feel differently about himself as a man; losing his sense of confidence about his social presence based on his sense of how men should act. Roger felt he could no longer meet these ideals as PD stripped away his bodily abilities, forcing him to feel differently about his body and his masculine status. Roger's account therefore exemplified the performative nature of masculinity; a performance that he felt he must maintain, but which was practically and existentially threatened by PD (Butler 1990; Spector-Mersel 2006). Such issues had direct consequences for men's experiential embodiment, redefining the dimensions through which men's bodies were felt, and how these feelings were themselves felt in relation to the social world.

Summary

In the above accounts I have focused on how men spoke of PD challenging their masculine status. Through the stories they told men enacted gendered ideals about their position in the world, using them to interpret their changing embodiment. PD's symptoms transformed a pragmatic embodiment highlighting the loss of activities and abilities men should possess. Men's visceral embodiment and the body's competence within the lifeworld became problems as their ability to control even the most intimate bodily functions grew more and more impaired (Nijhof 1995; Van Der Bruggen & Widdershoven 2005). Finally PD challenged an experiential embodiment, no longer able to easily performance and accomplish the 'natural' ideals of a masculine embodiment (Laz 2003; Connell & Messerschmidt 2005; Emslie *et al* 2006).

Gender and gendered expectations are therefore crucial to PD's embodied experience. In particular, masculinity was performative, accomplished through men's everyday acts and everyday encounters within the lifeworld. Men did not become 'weak' as a result simply of PD's physiological effects; they become weak as a result of changing embodied meanings. Weakness was experienced through men losing their ability to carry out stereotypically masculine labours. Their leaky bodies broke social norms about how masculine bodies should be seen and act (Nijhof 1995; Shildrick 1997). Difficulties with sex challenged intimate relationships, while the embodied competencies fundamental to masculine forms of social interaction became difficult to achieve. Crucially then, PD could be experienced as an erosion to the performative ideals of an ageing masculinity; how men's bodies should act. But importantly if masculinity is a relational concept, then it is open to change (Connell 1995; Calasanti 2010). Masculinity could be re-negotiated, it could be re-appropriated, it could be resisted and it could be remade. Through narrative, men could position themselves according to masculine norms, showing how despite PD they remained men. I now turn my attention to how men, through their various everyday acts, used gender and ageing as resources in order to comprehend PD's lived experience.

Part 2. Masculinity and ageing; resources for interpreting PD's lived experience

Masculinity and ageing featured much more widely than simply as a form of progressive emasculation. Previous research into the role of masculinity in men's health has shown that men can use different aspects of masculinity and masculine forms of behaviour in order to show themselves as remaining men. When men lose what is considered masculine competence in certain areas, they may reassert their masculinity through other domains, substituting certain forms of hegemonic masculinity with others more applicable to their own lives (for example as ageing men)

(De Visser 2009). An ageing masculinity also gave men access to a variety of discursive and embodied 'tools' through which they could make sense of PD. Gender norms could be re-appropriated according to men's individual lived experience, either reasserting their masculinities, or seeking new ways to assert their presence in the world as men (Chater 2002; Emslie *et al* 2006). And finally, all these experiences were themselves influenced by age and ageing, transforming what it means to be men in older age. I now discuss how men used masculinity when talking about PD, positioning themselves in relation to hegemonic ideals of masculinity. First, I examine how men spoke of their various occupations and activities. Second I discuss how men tried to show how they remained independent, active individuals despite PD, retaining autonomy and authority in their lifeworlds (Seamon 1979; Dyck 1995). I then discuss how masculinity shaped men's experience of care, from medicine and from their families (Seale & Charteris Black 2008). Finally I explore how men used masculine gender norms to negotiate their changing social relationships.

Reasserting masculinity through occupations, work and leisure

First, men's accounts of their masculinity were bound up with their occupations; employment; hobbies, sports and pastimes, household activities or other forms of productive work. Earlier I spoke about how men understood their growing weakness through their everyday occupations. But importantly, through their occupations they could continue to assert, or could re-assert a masculine presence in the world. By showing just how active they were, even in spite of their PD, men could reassert a masculine presence within the lifeworld (Benharoch & Wiseman 2004; Smith *et al* 2007).

First I consider the importance of work. Work was a key aspect of men's stories. Most of the men I interviewed had retired or left the workforce because of their PD. But a few were still working. For those of working age, employment was a key element of their continuing sense of self. Simon couldn't work, and as discussed in chapter six this contributed to a sense of isolation, leading him to look for other ways to fill his day. Despite Roger's difficulties, he still defined much of his identity through his work. Although over the retirement age, John was still in work. Like Roger, work gave John opportunities to be around other men;

GG *At work they, how do they support you with it (PD)?*

John *You've never worked in a shipyard have you.*

GG *I've never worked in a shipyard no.*

John *No. They're very, very to the point everybody. For example, (colleague) has just been diagnosed with cancer of the throat. First thing somebody said was, well you better get yourself back together, get out and sort yourself out. There's no sentimental...*

GG *Sentimentality.*

John *None at all.*

GG *And are you happy with that kind of culture?*

John *Yes. Fifty years of it. I love it. A nail's a nail. A tack's a tack.*

For John, the workplace was a fundamentally masculine place, associated with 'real men' and a lack of emotion or *sentimentality*; *'I love it. A nail's a nail, a tack's a tack'*. John had a number of difficulties with his work, but an assistant had been appointed to help him. His story was of him being *'in charge'* and *'needed'*; so essential to his workplace that management appointed someone to help him. Far from emasculating

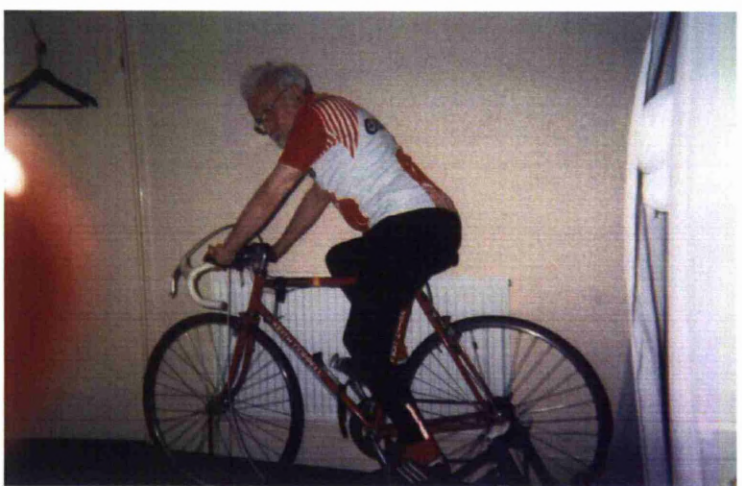
him, the help John received reinforced his importance at work was so needed that PD was no barrier. Unlike Roger's earlier account, John found the performance of a work based masculinity entirely natural and unproblematic, giving him opportunities to be around other men while asserting his masculinity through productivity and authority. Both Roger and John in their different ways illustrate the role that paid work played in the accomplishment of masculinity, even given their PD (O'Brien *et al* 2007).

However most of the men I interviewed had retired. Working lives remained important to men's biographical identity, but now their everyday occupations were concerned with their various hobbies, pastimes and leisure activities. Occupations were central to their stories, showing men as active and productive. Photographs were used to show the range of activities men continued to do, from gardening to sports, hobbies and exercise. Gardening was the most frequently discussed leisure activity (photograph 21). Sports also featured heavily. Henry played bowls in a local league. Tony occasionally sailed. David was a keen hill walker. John had largely given up golf but was thinking about playing bowls instead. Harold regularly went to a 'gym' and still played a range of games; snooker or croquet with friends (photograph 22).

Even in late PD men continued to talk of the sports they could do. Historically a keen cyclist, Tom now needed to use a wheelchair for much of the time. But he could still ride a bike using a turbo trainer (photograph 23). Hobbies, pastimes and sports provided a number of functions. First they gave men a way to train their bodies in order to maintain functioning. But they also gave men something to do, something to achieve and a continuing focus for their social lives. And through all these activities, men could show how active they were. Occupations now became a locus for activity, for a leisure based retirement based on men being physically active; a dynamic, successful form of male, active ageing (Calasanti & King 2007a; Tulle 2008).

Photograph 21. Hugh, standing proud over his garden

Photograph 22. Harold and friends playing croquet



Photograph 23. Tom riding his bicycle on a turbo trainer

Occupations were a way to show that the men were still physically active. However all the men had to recognise that these activities were growing harder. Yet their growing difficulty also gave men a means to reinforce their masculinity; to show that through stoically struggling on they could accomplish their difficulties. Everything now took extra effort, but this could take on positive meanings. Ever fond of using metaphor to communicate his experience, Simon described life as climbing a rock face. It was hard but he couldn't keep walking around it. One day he would have to climb it;

> *Simon In all the things I've done in my life I try to face what's in front of you, that's what it is. If you like that's the rock face, now I've got to climb over it, which is the way up. The problem is that the rock faces are getting steeper and I keep coming across them. And its possible to be tired, trying to get over them. You can sometimes look at the hill in front and think, ah do I really need to go over there. You know. No I don't need to go over there, I'll go a different way. The trouble is that if you go round every rock, you are never going to get up the top. Does that make sense. Sometimes you've actually got to get to it and say right I'm going to bloody well get up this one, one way or the other I'm going to get over it.*

By talking about their occupations in this way men showed that they wouldn't give up; they were stoic in the face of their PD. Alternatively they showed that they could adapt, that they could learn to work around PD and therefore accomplish their tasks despite their illness. Through both interpretations they could show that they carried on, and that by carrying on they could 'defeat' their PD.

Importantly, occupations were also judged through age appropriate forms; that they remained active but within the limitations placed upon them by advancing age. All the men claimed they were 'too old' to play physically active sports like football, cricket or rugby; not only were they beyond their abilities, but they would also be silly to do so. But it was important to show that they still did play sports. They may play less physically demanding sports but they remained sporty and competitive 'for their age',

and would continue to do so for as long as they could (Coates 2003; Tulle 2008). In sum, idealised forms of masculinity were defined through what Monaghan (2001) calls a vibrant physicality, based around particular forms of 'work', or around sporting actions. These were also expressed in new forms which were felt to be socially appropriate to men in older age (Spector-Mersel 2006). . Indeed men's stories of their occupations could reinforce their masculine status, showing how they stoically coped with PD's increasing demands, struggling on to continue to play an active role in life. By showing their participation in sports and other active pastimes, men could show that despite PD's effects they remained men.

Reinforcing masculinity through autonomy. authority and independence

A theme of many of the stories men told was about asserting their independence, autonomy and freedom; that they continued to do what they wanted, when they wanted and where they wanted (Secker *et al* 2003; Smith *et al* 2007). Men renegotiated the experience of care, interpreting it as 'help'. But in doing so, men could also show how they maintained their autonomy, authority and independence within the family. Secondly, men's stories of autonomy were not just linked to care. Men used their occupations to show that they could move freely in the world, according to their own wants and needs (Dyck 1995; Rowles 2000). Key to these accounts was driving; about more than just mobility; driving was crucial to a competent, autonomous and independent masculine self (Habermann 1996).

All the men I interviewed knew that PD would make them increasingly dependent. But it was important for men to find ways retain their independence, even if they were currently being cared for. Care could be told in such a way that men could retain both their autonomy and their authority. First, if care threatened to become too controlling

then men could find ways to resist. Simon noted that his daughter now worried much more about him, but he couldn't let these worries restrict his activities;

> *Simon. My younger daughter worries about me, and she'll say dad phone me when you get home and stuff like that, and I don't. Because I won't allow myself to be in a situation where because the kids are worried about me I have to check in. I don't, and there's two reasons for that. One, I don't like being in that controlled situation. If I always phoned in when I got home, erm, and I didn't one day, then the cavalry would be out. So I phone when it's convenient to phone, but they still say to me phone when you get home. And sometimes I will phone, but I don't make a habit of it, because I don't want them to put themselves in the worry position where they always worry about dad*

Simon was grateful for his daughter's attention, but his daughter's desire for him to call her could easily be interpreted as a form of surveillance, restricting his freedom and his agency. Simon wanted his freedom, to do what he wanted when he wanted without interference from his family. Therefore Simon resisted his daughter's desire to call her, seeking to avoid the potential reversal of his family roles and the loss of his own authority. Through this and a number of other acts; by not asking for help and trying to do things himself, Simon could therefore resist the gradual loss of power that the growing experience of care from family could bring (Ribiero *et al* 2007).

For those finding themselves being cared for, men's accounts of care focused on showing that they retained authority. Speaking of care as 'help' helped men to do this. Henry also gave a further account of his wife's growing care for him;

> *Henry My wife would never hassle or take any responsibility at all, it was as simple as that, you know. Well now she's taking on a lot more responsibility, and I am actually pushing her to do more for obvious reasons. Erm, she wouldn't drive with me in the old days, although she's driven all her life, or at least been eligible for a period of her life, she wouldn't drive with me in the car, because she felt that I was watching what she was doing,*

but now she will. She does it reluctantly, but to force her to do that, in the early part of my Parkinson's when I realised I could become err, debilitated in some way as far as the driving was concerned and all that, I would pull to the side of the road and say oh I'm having a bad headache again, I can't drive any further can you take it home. That's the way I got her to drive, and now she's quite prepared to drive with me in the car. And that sort of thing. So a number of areas if you like. On the financial side she's never had to look through anything, but I keep getting her to try and look at the bank statements and work out different things for herself, you know.

GG Why did you feel that you had to do that with your wife?

Henry Cos I don't think she was capable of suddenly being on her own, with a state and her character as it was at that time if you like. I mean my wife was very submissive to me, to my, I ruled the house, I was the boss of the house you know.

Henry used this story to negotiate his changing family relationship, maintaining his biographical authority over his wife. Rather than losing his authority he was 'training' his wife to take more responsibility for his tasks, and to cope after he was gone; either because of death or entry into residential care. He knew his life was finite, and he would die first. He therefore needed to prepare his wife for this event so that she could live life without him. The growing assistance she needed to give in instrumental care; of washing or dressing contradicted this story so they were largely left out. Instead Henry focused on areas of stereotypically male responsibility; *'I got her to drive'* or *'the financial* side'. Rather than losing power in the marital relationship, Henry's story is told in such a way to maintain masculine authority over care (Calasanti & King 2007b). Henry exemplified an approach used by other men to a lesser extent in which he is the *'boss of the house'* and head of the family. Indeed such a position could be used to normalise care, reinterpreting it as part of the woman's responsibility; for example seen in Tom's assertion in chapter seven that caring fell naturally under the woman's responsibility; something his wife and daughter should do. In such

accounts, care could be taken for granted, subsumed within the gender division of the household and therefore viewed unproblematically. Men therefore used masculine ideals around responsibility and authority to negotiate care, finding ways to account for their experience which prioritised their position in the caregiving relationship, while managing the dependency and burden-hood growing within men's everyday experience (Ribiero *et al* 2007; Calasanti 2010).

Movement was also central to autonomy; the ability to travel, to go when and where they wanted. If any single activity best demonstrated the importance of this experience it was driving (Habermann 1999; Bramley & Eatough 2005; Singh *et al* 2007). Driving was the key means through which men asserted their continuing independence. Those few who couldn't drive mourned its loss, while those who did drive feared the day when they had to stop. But to continue with driving, the act of driving and its subsequent meanings had to be remade. The embodied actions learned many years past were now becoming problematic, the complex co-ordination of arms and legs needed to manipulate the controls of a car became more difficult;

> *Ian: Steering is slow, the gear lever is slow, the pedals are slow, even in emergency braking the pedals are still slow, because you've only got to move your foot. And you don't slam them on, even in an emergency stop. Cos the brakes, modern brakes come on automatically. So none of it, the only thing is the thinking, and it's that thought process, that's taking a little bit longer than it used to, so I've slowed down to accommodate it.*

But this experience could also be transformed. Because Ian now had to think about the act of driving much more, he could claim he was now a much better and therefore safer driver *'I've slowed down to accommodate it'*. Through the problems they faced, men could once again show their rational, problem solving nature, demonstrating their continuing competency and responsibility.

Driving was also intimately associated with a 'macho', aggressive form of masculine status and power. Roger obsessed about Land Rovers, on one occasion buying one without talking to his wife and despite his serious financial difficulties. Indeed his wife worried this was abnormal, that he was becoming more and more out of control. Roger described himself as an aggressive driver, driving fast, taking risks, dominating the road, even bullying other drivers; a macho expression of masculinity (Courtenay 2000);

> *Roger* *I find that I need to keep driving, to keep you handy. Once I'm in the car I feel I'm master of my own destiny again you know. That's the biggest oh, that's one of the biggest crutches for me I think is to stay independent with your car. It's a man thing and I think it helps tremendously for me, you know. Cos when you are there in your car, you are equal to anybody. If not better, in my own mind and there again maybe that's where I have a particular penchant for 4 by 4s, excuse me. Two reasons, in one of them you can get anywhere for the sake of walking yeah, walking's the problem. But you also feel more masterful I suppose really.*
>
> *Wife* *Its cos you're a man isn't it.*
>
> *Roger.* *Well, it gives me a buzz, because you feel more powerful in that than, not that I push anybody off the road but it's just a psychological thing isn't it. Like erm, people have sports cars, like a phallus or something. But for me four wheel drive is you know, I just feel secure in it, I know I can drive it and its competent, you just feel you, you are, you are a normal man in it. Or better if you know what I mean.*

It would be easy to write of Roger's account as a masculine cliché. But it was more significant; driving a large car became one of the few remaining means for Roger to perform a successful masculinity now thought to be in decline. Roger struggled to walk, but behind the wheel he felt 'equal to anybody'. Behind the wheel his PD is invisible; hidden from view. Others will not judge him as a broken wreck, but as a man, for good

or for ill. Others spoke less strongly about driving but used similar rhetoric; in a physical body declining in its abilities, growing more distant from an idealised manhood, driving was one of the few activities where they could reassert a competent masculine self. In essence, driving was one of the few activities in which Roger, along with several others could feel like a 'normal' man again.

In summary, throughout men's stories, and despite their PD, men could reinforce an autonomous, independent masculine self. Autonomy in PD therefore becomes a complex issue, negotiated through men's changing place in social and family life which themselves changed as PD progressed. Autonomy and independence ceased to be either/or; to be independent or dependent (Oldman 2003; Secker 2003). Instead it becomes a continuum, men gradually facing a growing dependency but also finding new ways to sustain authority and autonomy as PD worsened (Ribiero *et al* 2007; Calasanti 2010). Autonomy could be asserted through men's acts; with driving being the most frequent act in which men showed their independence. Driving, along with all the other activities important in men's lives could no longer be taken for granted, but men needed to show that they were still competent behind the wheel. In doing so, they could show that, at least for a time they could be as able, as competent as all the other men they encountered within their lifeworlds.

Seeking alternative forms of masculinity

All of the men to some extent engaged with what they thought were idealised forms of masculinity; around being strong, able, autonomous and independent. Most of the men found themselves struggling to meet many of these norms. The most common narrative was of 'struggling on', which as exemplified by Roger could have significant consequences for men. But a few also claimed that they tried to find alternative ways

to account for their presence in the world as men. Tony, alongside a few other men distanced themselves from many ideals of male gender identity. Tony and Simon were both of working age but could no longer work. But both also spoke about how they sought alternative identities, in their case around pursuing an active, stimulating form of leisure based retirement. And men also spoke about masculinity in different ways in order to negotiate their contact with medicine; to show that it was beneficial for men to seek help. Both men therefore sought to distance themselves from what they considered masculine expectations they struggled to meet, instead speaking of these issues as unimportant in their lives.

Tony was the exemplar of seeking alternative ways to define himself in relation to many (but importantly not all) idealised notions of a middle aged masculinity. Approximately 15 years earlier, Tony had suffered from what he called a nervous breakdown. Since his breakdown all aspects of Tony's life had transformed. Tony had gone through a divorce, moved home and had been diagnosed with PD. Tony still suffered periodic bouts of anxiety and depression. But slowly, over many years, he had learned to create a new world for himself based around new forms of existence; not least by leaving the 'rat race' and instead living a rural, almost isolated existence. Importantly, all that he had learned during this period was now helping him to deal with his PD.

Many of these experiences had taught him to discard many of idealised expectations of being a man (Connell 1995). But in doing so he focused his identity on alternative forms, themselves expressions of masculinity but in different forms. Tony spoke of two core elements through which he differentiated himself from the stereotypical 'macho' attitudes of other men. The first was his experience of contact with medicine. He was well aware of the demands of dealing with medicine, through his PD and earlier

psychiatric care. Although he had experienced numerous problems with his care over the years, his experiences of illness felt him feeling that the idea that men should avoid medical help for their health problems was frankly nonsense;

> *GG* *Has Parkinson's disease ever affected how you see yourself as a man at all?*
>
> *Tony* *Erm, not really, I don't, I've never been into that sort of thing, you know, I've never had, I don't think I've ever had sort of macho problems. (...) You know, I just (4) I don't think its ever sort of, ever bothered me that much. Yeah, I'm aware of it, inasmuch that some people are sort of that way inclined and other people aren't. But I mean, (friend) he, you see, (3) he's had, cancer of the kidney and he went into denial. And if you start, if you mention hospitals he hates it, he can't deal with, as far as, as far as they're concerned, illness doesn't happen. You know, they can't manage it. So I regard that really as that's his problem, not mine. (laughs).*

Instead of rejecting medical help medicine had become the key tool in keeping him healthy, both mentally and physically. The coda of Tony's account is that proper men seek help, remaking help seeking as a reinforcement of masculinity rather than as emasculating (O'Brien *et al* 2005). Simon also told a similar story, drawing on his earlier experiences of caring for both his wife and an autistic stepson to position himself in relation to medicine;

> *Simon* *I've spent so many years embroiled with the medical profession through my son and this (PD) is just an extension of that. I've learnt how to deal with them and recognise that I am the customer. And increasingly I'm not prepared to stand on protocol, and, I don't mean this disrespectful, and I know (consultant's) a very good chap, but I don't see a consultant or a doctor as an important person, who looks down upon me from a big desk in front of me, I see him as another bloke.*

Making an explicit connection between his past experiences and current medical care, Simon used his knowledge and expertise of medicine to position himself as a '*customer*', putting him on a very different footing than his view of being a 'patient'.

Both Tony and Simon rejected ideas that men should resist seeking help from medicine; that they should be autonomous, macho, and disinterested in their health. Tony claimed his prior experiences of illness had left him more accepting and in tune with his emotional states; a better type of man. Simon felt that by engaging fully with medicine he could find out as much as possible about PD, used in order to find successful ways to deal with it. Avoiding medicine wasn't the answer; indeed with treatment they could lead a fuller, more active life than they otherwise would. Far from help seeking being a weakness it becomes a positive; a means of showing responsibility for their individual health, and making sure they could do as much as possible for as long as possible (Johnson *et al* 2011). As a result, through an engagement with medicine Tony and Simon, along with many other men could re-appropriate masculine ideals, leaving them feeling better able to cope with the demands of PD, and therefore more able to live an active and productive life.

In addition, Tony, who at 62 was close to retirement but still of working age also rejected the idea that the only successful form of being a man was being in work. Tony hadn't worked for many years, and so thought very differently about its importance to his life;

> *Tony I think that's my way of overcoming this thing where, erm, people use the R word, retirement. And (1) they seem to equate it with the end of life, the end of your useful life. Erm, me mate, wouldn't give up work until he was about (4) he was about sixty eight sixty nine, and I kept on at him, and his lad kept on at him, will you tell him. I said I've told him until I'm sick of telling him. He thinks he's immortal, and he thinks, you're not a man,*

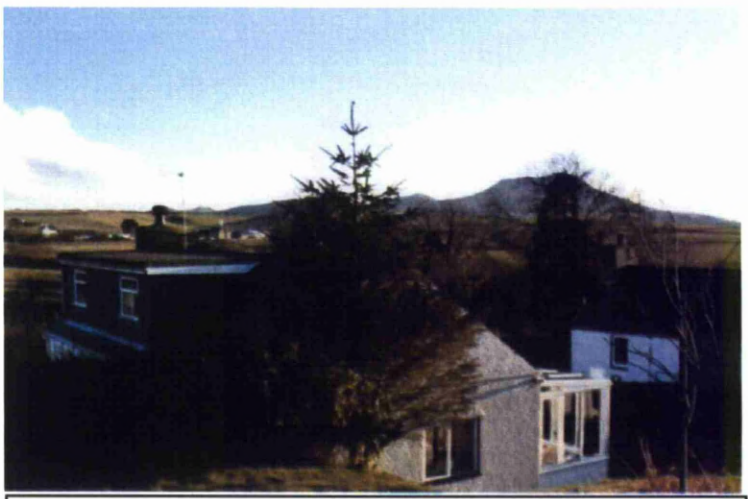
you know, I think (friend) thinks if you are not working, you're not a man. (...) I said its not retirement, it's a second go at life, and that's what it is to me. You've had one bit, and you've done that, been there, done that, okay, my change as forced on me, virtually, erm, but, when I'd sort of recovered my, what little wits I've got left, erm, I preferred to look at it as an opportunity.

Tony tied his friends thoughts to what he criticised as a 'macho' form of masculinity. The equation of retirement as *'the end of your useful life'* was seen as a pointless, even harmful act. Tony described life as being about more than work and its associated meanings. In particular the idea that *'if you are not working you're not a man'* was rejected. Instead Tony had learned that life was to be enjoyed as much as possible; he had been given *'a second go at life'*. This new life had been to some extent forced on him, while PD now meant it also had new boundaries. Given his PD was progressing many of the things he did now he wouldn't be able to do in the future. Therefore if time was finite it was better to try and enjoy what was left, rather than spending all his time at work or worrying about not being able to work. Given its new finitude, life now had new priorities. a kind of existential awakening to a new, finite form of life, with what was left having to be enjoyed.

However Tony's rejection of these two predominant meanings of masculinity associated around work or help seeking did not mean that Tony or those telling similar stories; Ian, Bob, or Simon rejected all elements of masculinity. To resist many common place, common sense notions of masculinity is itself a gendered act (Connell 1995; Emslie *et al* 2006). Rather than masculinity being a single, unitary concept, men, exemplified by Tony, could use different elements of wht they judged to be a successful form of masculinity to compensate for the loss of other aspects of what they felt constituted a successful man (De Visser 2009). Now, instead of associating himself

with his work place, Tony and Simon tried to communicated a masculine identity through alternative norms; for example around physical activity and leisure.

Photograph 24. Simon flying a model seagull



Photograph 25.Tony's home in rural North Wales

Tony's life, along with Simon's, was now spoken of as being focused on a slower pace of life, one they could cope with. But this was still defined by an active form of rural leisure, of walking the dogs, of sailing, of flying model aircraft, of restoring an old land rover or old motorbikes, and enjoying the slower, rural pace of life where they lived; what both men saw as a more authentic existence. However their new lifeworlds, and

the new identities Tony and Simon had built around them were facing a number of practical and existential challenges. A life of active leisure, based around activities like sailing were becoming harder. Tony couldn't take his boat on the water without being accompanied. Activities were dependent on their physical abilities on that day, some days Simon simply couldn't manage to get out to fly his models. Even walking Tony's dogs on the local beach was becoming more problematic as he slowed down, making him question how much longer he could look after them. Such thoughts were distressing as without his dogs, Tony would lose both his main day to day company and his main reason for leaving the home. For both men, living in a slower paced rural idyll was also becoming more difficult. For Tony, the quietness of his home was slowly changing (photograph 25). Instead as his mobility declined he feared becoming more and more isolated, raising the very real fear that at some point in the future he might have to leave, to give up this idyllic, independent lifestyle. It wasn't just that PD challenged a mainstream form of masculinity; it could also threaten any alternative forms of masculinity men tried to express. Tony's choice to live in a quiet part of the world was threatened as he feared he would eventually be unable to stay. Simon had already chosen to go through this, moving from an isolated mountain village to a village on the outskirts of one of the major towns in the area; a halfway house where he still had his privacy, but was nearer to any amenities if needed. And again, for someone of 53, he did not expect to have to deal with such concerns until much later in life. PD meant that a life defined around an active but relaxed form of leisure was threatened as the embodied activities an alternative masculine self was based on were also being lost.

In summary, instead of trying to show that he met many of the central ideas around how men should act in the world, Tony chose to reject them, relieving himself of their

pressures and finding what he felt was an alternative way of living. However these alternative masculine meanings were themselves all experienced through the body and its changing, abilities. As a result they also came under threat from PD, questioning how long he could continue to use these alternative ways of defining themselves as men, and what he would do if they failed. Whether engaging in predominant, hegemonic ideals of masculinity, seeking to re-appropriate them, or using alternative definitions, all men faced a body declining in its embodied acts; challenging these identities and the sense of self expressed through them.

Summary

In this section I have discussed how men use their expectations of masculinity to negotiate their illness according to their individual circumstances. Men's experience was more complex than simply saying that PD threatened men's ability to meet the tenets of a idealised, 'hegemonic' form of masculinity (Connell 1995; Solimeo 2008). Men's experience of masculinity was not simply negative, something they could no longer achieve (Calasanti 2010). Instead men drew upon different aspects of hegemonic masculinity to communicate themselves as successful men, compensating for lost elements of their masculine identity by refocusing on different elements they could still meet (De Visser & Smith 2006; De Visser 2009). Through their stories men could show that they remained physically active, reasserting their presence in the world as men. Masculinity also gave men a means to negotiate informal care, interpreting it in a way that allowed men to retain authority within their family relationships or resist the control of their families. For some these resources were organised around work, for others they were forms of physical activity. For many they were used to negotiate formal and informal care, resisting meanings of dependency (Twigg 2004; Ribiero *et al* 2008). And a few spoke of rejecting many male gender

norms, instead finding alternative ways to define themselves as men (De Visser 2009). As a result, demonstrating that they still remained men could support their well-being (Emslie *et al* 2006; Calasanti 2010). However these were also complicated by PD's experience. For many masculinity had to become a conscious concern, something they had to perform to others, masking a 'true' self (Spector-Mersel 2006). And eventually, many of these idealised resources, whether based on hegemonic ideals or alternative forms could begin to fall apart as PD overtook their ability to perform them. Therefore masculinity's performance was influenced in often profound ways by PD, eventually coming to question the very nature of how masculinity is accomplished through men's acts; a further fundamental structure of the lifeworld facing a profound challenge in PD.

Conclusion.

This chapter brings masculinity to the foreground. Gender is a key discursive structure through which men could make sense of the various problems PD brings to their lives (Fleming 1999; Calasanti & Slevin 2006). Masculinity exists as a social structure through what Connell (1995) famously described as hegemonic masculinity (see also Spector-Mersel 2006; Robertson 2006b; Robertson *et al* 2010; Calasanti 2010). Hegemonic masculinity is not the most common form of masculinity, instead it is its idealised, most powerful form, what men should be like rather than what they are (Connell 1995). In addition to being associated with being strong, physically active and wealthy, hegemonic masculinity is increasingly prioritised by youth and middle age (Connell 1995; Robertson 2007; Thompson 2006). Connell's (1995) original conception was both monolithic; there is only one dominant form of hegemonic masculinity, but is also relational; it can and does change (Connell 1995; Calasanti 2004).

The goal of this chapter has been to ask how men with PD engage with masculinity within their everyday lives. In order to consider this question we must also consider PD in relation to hegemonic ideals. To some extent all the men I interviewed engaged with hegemonic forms of masculinity, even if they couldn't meet them. Many men found that PD threatened a masculine identity defined through its ideals. Men felt increasingly weak, lost control over even basic bodily functions, and could potentially lose much of their status, authority and power. But men's experience of masculinity in PD is far more nuanced that simply claiming that PD emasculated men. The pressure to conform to hegemonic ideals of masculinity could exacerbate experiences of illness, but also gave many of the men I interviewed a means to make positive meaning from their PD (Johnson *et al* 2011). Men could re-appropriate masculine meanings, using differing elements of what they saw as masculine ideals in order to maintain their presence in the world as men; for example showing themselves to be physically active *despite* their PD, or reasserting their authority in the face of informal care (De Visser & Smith 2006). And they could reject many of its norms, for example around work, instead seeking alternative forms; e.g. around active leisure. While-ever they could meet them, meeting these ideals could be conducive to well-being as men could reaffirm their status as active, productive men, successfully accomplishing what they saw as previously taken for granted masculine ideals. Through such accounts, the stories men told about their PD illustrate how older men continue to engage with hegemonic and alternative forms of masculinity, and how their own behaviour relates to hegemonic gender norms (De Visser 2009).

Importantly hegemonic meanings of masculinity were also interpreted and re-interpreted through age (Calasanti 2004; 2010). Ageing and gender intersect to create new social structures and new lived experiences. When making judgements about

men's masculine status they drew on wider social discourses around old age, either as a period of illness and decline, or as form of successful 'active' ageing (Calasanti & King 2005; Thompson 2006). Spector-Mersel (2006) has argued that currently older men face an absence of what she calls ageing-masculinity scripts; within hegemonic ideals of masculinity older men are redundant, almost invisible, receiving little guidance about how older men *as* older men should live according to its ideals. By forcing older men to live according to a hegemonic form of masculinity defined by the goals of youth (for example being organised around work), older men are automatically marginalised by its ideals, even before illness, frailty and the various other experiences common in older age (Calasanti 2004; 2010). For Spector-Mersel (2006), Connell's original, single definition of hegemonic masculinity ignores the fact that different groups of men have different ways of defining what hegemonic masculinity is. Even though hegemonic forms of masculinity have little concern for the lives of older men, older men continued to engage with their ideals. But in their everyday lives and in their everyday stories, older men remade these ideals into age appropriate forms. (Laz 2003; Spector-Mersel 2006).

Spector-Mersel's (2006) claim is borne out in my study. Many of the tenets of hegemonic masculinity; for example physical activity, independence and autonomy or authority and power all remained important as means for men to negotiate PD's lived experience. Through their everyday acts men with PD could still associate themselves with masculine activities. But these meanings were remade according to their current age and current abilities. Monolithic definitions of masculinity based on youth were no longer achievable. But the men I interviewed, all with PD did not try to compare themselves with all men. Instead they compared themselves to other men within their own contextual lifeworlds; put more simply to the worlds of older men. Men's worlds

were full of older people, of older men, of others with PD. Men made judgements appropriate to this world; in which meanings of masculinity directly associated with youth had little meaning. It was through these contextual judgements, experienced through the everyday acts of men's lifeworlds that men's age and gender judgements played out (Spector-Mersel 2006; Solimeo 2009). This does not assume that wider structures, for example of hegemonic masculinity are unimportant; indeed they are, however older men engage with them according to the contextual realities of their lifeworlds; to understand how they play out, we must understand masculinity through its expression in older age. As noted by Calasanti (2010), this remains an important area for future gerontological research.

Men's experience of both ageing and masculinity also illustrates a further important element of its experience; that both gender and ageing can be thought of as performances, something men 'did' (Butler 1990; Laz 2003; Spector-Mersel 2006; Calasanti 2010). By thinking of ageing and gender in PD as performances, or as Laz (2003) argues as accomplishments, we can relate men's individual lived experiences to these wider social structures; to forms of collective work which contribute to our shared experience of the lifeworld. Such structures include the notions of hegemonic or alternative masculinities described above, and social discourses on ageing, as either a period of ill health and decline or as an extended middle age (Arber *et al* 2003; Pickard 2010; Gilleard & Higgs 2011). Importantly, both these performances, as seen in this chapter and throughout my wider thesis are accomplished through men's everyday acts. Despite men worlds being focused on being shared with other older men, wider structural notions of masculinity still played a role; even if remade into age appropriate forms. When men spoke about carrying on with physical activity they continued to make statements about their presence in the world as men. But they did

so through claims made according to their age; that they were performing better than their peers, were doing well 'for their age', or where experiencing something that went beyond 'normal' ageing (Solimeo 2009). Through men's everyday acts they therefore tried to make sense of this often complicated experience, making judgements according to social expectations about older age. To examine PD's gendered experience, alongside the other various illnesses of ageing; we must therefore consider it in conjunction with age (Krekula 2007).

In a final point, once again PD's progression illustrates the dynamic nature of PD's lived experience. Namely, the gender-ageing performances and their consequences for men's lifeworlds are subject to continual change. The idealised accomplishment of an ageing masculinity through occupations and activities faced continual challenge in PD. Men used their acts in relation to gender to tell stories about PD. But these stories were complicated by PD's progression, changing how men thought of both gender and ageing. Men could find new ways to emplot their stories; David could walk the lower paths instead of the mountains. But they didn't have the same meanings. Eventually the physiological realities of PD meant that even age appropriate forms of male activity and their associated meanings could fall away, challenging their core sense of self as they could no longer do what they once could (Meadows & Davidson 2006). Eventually men could find themselves no longer able meet the ideals of masculinity, while their expectations of older age could no longer explain their experiences. As Peter put it, '*I expected to be slow but not this slow*'. It was not guaranteed that men would eventually lose their sense of being a man; some could maintain it even in severe PD. But as PD progressed and its impairments grew more and more profound, successfully performing a competent masculine self grew harder and harder. Eventually it would become impossible for many men to continue to think of themselves as successful men

based on the ideals of hegemonic masculinity. An ageing, masculine self in PD was therefore a complex, shifting entity, continually having to be revisited, and for some, eventually failing. In conclusion then, gender and ageing are at the heart of how men made sense of PD, and how they experience a shifting lifeworld. To understand PD's lived experience for men, we must therefore be concerned with an ageing masculinity.

Chapter 9. Discussion & Conclusions

Introduction

In this thesis I have explored men's experiences of living with PD, a progressive neurological illness with dramatic consequences for men's lifeworlds. To conclude this thesis, I summarise its major findings and discuss the contribution they can make to the medical treatment and care of men with PD. I also consider how PD also informs our wider knowledge of chronic illness and its experience in relation to both gender and ageing. First I discuss the key findings of this thesis and what they can tell us about PD. Second, I discuss the implications of this thesis for the delivery of PD services. Finally I reflect on the limitations of this thesis, its conduct, and areas for further research arising from my own findings.

Part 1. Summary of main findings

Here I summarise the central findings of this thesis. I do so in two parts; first I discuss PD's lived experience and men's changing experience of the phenomenological lifeworld. After this I discuss how PD's embodied experience is influenced by gender and ageing.

PD's lived experience

PD leaves few areas of a man's life untouched. By affecting movement, PD comes to challenge some of the most mundane, taken for granted activities of everyday life. Walking, talking, moving through space or interacting with the various objects making up the lifeworld ceases to be achieved in a smoothly flowing manner. Instead they become halting, difficult and slow. These implications go far beyond the body's physical movements; they transform men's sense of the lived body. In PD the body is

no longer experienced as a unity, oriented to men's intentional acts. Now the body has to be told when and how to move. Even the most intimate, hidden bodily processes; swallowing, urination, defecation or the effects of adrenaline have to be thought about, observed and managed. The body in PD also becomes known through its continual uncertainty, a body that fluctuates; between moving too little and too much, or between feeling *'hyper'* and feeling *'like a zombie'*. In sum, the body ceases to provide a stable, absent platform for the everyday life characterised by the phenomenological natural attitude (Leder 1990). Instead PD leads to what Van Der Bruggen & Widdershoven (2005) describe as a 'well considered body'; a body that has to be thought about in almost everything the men did.

These changes to the lived body are also felt throughout the existential structures of the lifeworld; the body, its position in time and space and its relation to other people (Merleau Ponty 1962; Haahr *et al* 2010). Receiving greatest attention in men's accounts, the lived body also changes the existential structure of lived time (Schutz 1971; Toombs 1990; Brough 2002). PD places new demands on the temporal organisation of the body; driven by the fluctuating, cyclical nature of PD's symptoms and the constant need to take medications. The structures of everyday time, what Schutz (1945; 1971) called a common time perspective transforms. All of the mundane acts comprising our everyday experience; washing, dressing, eating took more and more time and effort to complete. Paradoxically this made men's lives seem busier, more of their time and effort taken up with these actions instead of the activities that gave life meaning. As a consequence, the taken for granted structure of lived time breaks down in PD, instead being replaced by new patterns of organising time, all of which served to further alienate them from a shared lifeworld.

The changing experience of lived time also threatens a biographical self and its projection into an anticipated future (Ricoeur 1980; Bruner 1987; Van Der Bruggen & Widdershoven 2005). The past becomes tinged with loss, but is also remade in the face of PD; men trying to understand when their PD started, why they had it and what they could have done to avoid it. In addition the future ceases to be open to a biographical self. Instead the future becomes deeply finite, characterised by fear; known through what Simon called an 'approaching storm'. Each of these orientations to time in turn shape the stories men told in the present, further reinforcing just how much their lives had changed. In sum, in disrupting the lived body, PD also disrupts the essential structures of lived time, alienating men both from the everyday flow of a common time perspective and from their orientation to narrative time; the timescales over which we constitute our biographical selves (Ricoeur 1990).

All the men I interviewed knew their bodies were changing, the demands of everyday life therefore required them to respond to their illness. It is here where men tried to show how they came to terms with PD's changing embodied experience. Men's attempts to cope with PD were most often focused on their accomplishments; an active embodiment achieved through physical labours and productive forms of leisure; sports, DIY, gardening, hobbies or pastimes (Habermann 1999; Wilde 2003; Laz 2003). But crucially, to achieve this men's sense of their own bodies, the place they occupied in the world and the meanings attributed to them had to change. Harold, long a sporty person, now focused on the simple joy of taking part rather than on winning. Dafydd and Bob had to find new ways to relate to their bodies; working around PD's various obstacles in order to accomplish their everyday projects. Men could find other ways to cope with PD; by seeking information, by telling others about their condition, or by using humour to show how they dealt with PD. Through these acts, men could

accomplish their everyday goals, and therefore could reconstitute an active, embodied self, threatened by PD, incorporating PD into their biographical self. However this came at the expense of a body held in constant awareness, further alienating men from a shared lifeworld as some of the most fundamental bodily activities came to hold different meanings.

Finally PD is not a static illness; it fluctuates, it is uncertain and it is constantly changing. Most crucially 'it gets worse'. What works as a means to deal with PD at one point in time may not work in the future. This experience has profound and continuing consequences for men's lifeworlds. Not least, continuing to maintain a coherent, masculine biographical identity grew harder and harder to achieve. Harold, Tony, Simon, David and John were all 'sporty' but struggled to maintain these identities as their abilities continued to decline. And in later PD when simple activities like washing or dressing grew more difficult, PD began to affect men's basic, essential embodied competencies. Ian, Roger, Bob and Hugh increasingly struggled to cope with the loss of their abilities, questioning how they would cope in the future. In order to successfully manage their PD, men had to continually attend to their changing embodiment, an experience which could eventually overwhelm men's attempts to make positive meaning from their illness. In such an experience PD threatened men's continued participation in the lifeworld, leaving little alternative but to slowly withdraw from their shared expectations of a physically and socially active life.

PD, masculinity and ageing

Given that our lifeworlds are shared, PD's experience will also be influenced by wider social practices, each contributing to the shared structure of the lifeworld. PD's experience has a clear gendered dimension. When men talk about their bodies, they

are also talking about *men's* bodies. When men accomplish their everyday acts; they are also doing gender. PD's effects cannot be divorced from masculine forms of embodiment (Calasanti 2004; Thompson 2006; Robertson *et al* 2010). First, a common feature of men's talk was that PD threatened to emasculate them. PD made them weak, it took away their sexual potency, and it stripped them of control over the most intimate physical and emotional functions. In doing so PD challenged men's masculine status as they now struggled to meet what they saw as embodied ideals of masculinity; based around physical strength and dynamism, their ability to move through the world, to do things with others, and to retain authority and autonomy within their social relationships (Connell 1995; Robertson 2006b).

Men also spoke of gender as a means to make sense of PD's experience; a resource through which they could come to know their PD. When men spoke about their changing bodies they tried to show how they acted according to what are perceived as masculine ideals (Thompson 2008). Strength and weakness; energy and power; aggressiveness; sexual potency; the ability to control the body; physical activities or technical skills; authority and status; autonomy and independence and emotional control were all features of men's talk about PD. These were threatened by PD, but they could also be renegotiated, spoken of in such a way that men could retain, even reinforce their masculine status (Emslie *et al* 2006). Several men spoke of their experiences in ways which showed that they continued to meet masculinity's embodied norms. Henry found himself being cared for, but by instead claiming that he was 'training' his wife, he could reassert his authority in the face of the growing experience of care. Simon resisted his daughter's well-intentioned attempts to monitor his behaviour, unwilling to give up his autonomy. Harold, Hugh and David showed how they struggled on with their household tasks, that they overcame their

difficulties and by doing so remained independent and active. And by talking about work, John could show how he took part in both productive labour and a masculine, workplace based camaraderie. When men talked about many of the effects of their PD, men also tried to show how they responded, and how through these responses they continued to accomplish a successful form of masculinity; they continued to see themselves as successful men.

However some of the men struggled to meet the embodied norms of a performative masculinity, bringing its experience into relief. For many men masculinity's performance becomes increasingly visible. Roger now struggled to act as he felt men should act; with strength, aggressiveness, vigour, power and authority, isolating him from a lifeworld he previously easily inhabited. Other men also felt unable to meet what they saw as masculine ideals of physical strength and productivity, but instead of struggling to meet these ideals they instead expressed their masculinity in alternative forms. Tony rejected 'macho' ideals around masculinity, for example of physical productivity, around the rejection of mental illness, or based on the refusal to seek medical help (O'Brien *et al* 2005; Emslie *et al* 2006; Robertson 2006b). Instead Tony tried to show a masculinity which focused on an active, leisure based retirement, sustained with the help of his PD treatment. By doing so, he rejected some masculine tenets but reinforced others. Masculinity is a relational concept, but even when men tried to reject certain idealised forms of masculinity, they did so by highlighting alternative forms (Connell & Messerschmidt 2005). Whether they followed hegemonic norms or sought alternatives, men continued to use masculine ideals in showing how they responded to their PD.

Furthermore masculinity was also intertwined with ageing (Calasanti 2010). PD's symptoms were also judged in relation to men's age (Solimeo 2009). Ageing with its

associations with slowness and reduced mobility, rather than illness, pain and suffering gave men the clearest way of interpreting PD. But these judgements differed according to men's expectations of their chronological age. By making younger men seem old, PD was thought of as an abnormal state, distancing them from what men in middle age should be capable of, physically (being strong) and socially (being in employment and positions of relative power). In contrast, for older men PD could be subsumed within a wider narrative of older age; expected as part of an older age characterised by illness and decline (Solimeo 2009; Calasanti 2010). Men of younger ages; Roger, Simon and Tony knew they were ill, but it was their expectations of ageing rather than their experiences of illness that best accounted for their changing embodiment in PD. In contrast Tom, Bob, David, Dafydd and Peter spoke of expecting some form of illness given their advancing age. By speaking of older age as a period of illness and decline, older men could incorporate PD into their biographical identity, as something other than a world changing event (Sanders 2002; Faircloth *et al* 2004a). Thus men's judgements of PD and its effects were made according to their socialised and embodied expectations of how bodies should act as they age; as slow, in pain and increasingly immobile, and about what older age is; a period of ill health requiring medical intervention (Laz 2003; Calasanti 2010).

However these gender and age based judgements also changed as PD progressed. As men lost strength and stamina and later even basic mobility and control over the body's functions, it grew harder and harder for men to assert a masculine self even taking their age into account. Nor could men easily blame their increasing symptoms on their age. PD's symptoms eventually grew too severe, or diverged too much from their expectations of old age to account for their experiences; '*I expected to be slow but not this slow*'. Therefore, although ageing and masculinity both provided men with

means to make positive meaning from their illness, as PD progressed it grew harder and harder to do so, instead leaving them to adopt an identity associated with illness, increasing immobility and dependency; all threatening a biographical, masculine self.

Summary

In summary, this thesis supports the findings of other studies of PD's subjective, lived experience; showing that PD disrupts the unity of the body, self and world (Habermann 1999; Bramley & Eatough 2005; Solimeo 2009; Stanley Hermanns & Engbretson 2010; Haahr *et al* 2010; 2011). But PD is also shown to be a complex bio-psycho-social process, determined both by PD's biological reality, sufferer's individual experiences, and a range of social structures and practices, not least ageing and masculinity. All PD sufferers, whether male or female experience a variety of consequences from their illness, remaking their sense of the body and its position in the temporal flows, spatial structures and social relations comprising the lifeworld. But although PD's physiological symptoms may be similar for men and women, or for men of different ages, the meaning of these experiences differs greatly. Men make sense of PD's somatic and sensory experience through a gendered lens, based on their expectations about what men do, and how they should be seen and act in society (Solimeo 2008). PD is also brought into relief in different ways as men make judgements about their position in the lifeworld according to their age and social expectations of ageing. To conclude, more than simply a movement disorder, PD left few areas of men's lives untouched (Van Der Bruggen & Widdershoven 2005). In order to understand PD, we must examine these lived experiences, but we must also situate them within their wider social practices. By doing so, we can gain greater insights into how an illness such as PD shapes men's lifeworlds, and how medicine and its practices can best intervene in men's lives. It is this issue that I now turn my attention to.

Part 2. Men's experience of PD; its implications for clinical practice

Given the failure of PD services to consider all the impacts that PD brings to sufferer's lives, my findings raise questions about how equitable, person centred and age and gender sensitive services for those with PD can be delivered (Solimeo 2009). Current neurological approaches to PD do not adequately consider the different needs of differing groups of PD sufferers, or how their experiences and needs change according to gender or indeed as they all continue to age. I now discuss how this thesis can contribute to improvements in service delivery in PD. First, using a model for men's journey through PD I discuss how and when interventions in PD could occur and some of the therapeutic issues they should seek to address. Second, using current NICE clinical guidelines for the delivery of PD services in the United Kingdom as a point of departure, I examine some of the current gaps existing between current guidance for PD treatment and its practice. Drawing upon men's experiences of living with PD I make suggestions about how these gaps influence men's lives, and how some of these gaps may be filled.

A model of men's journey through PD

The predominant neurological approach to PD; as a progressive disorder caused by changes to neurophysiology and treated via pharmacology has struggled to engage with many of the practical and existential issues PD sufferers routinely face. In addition PD's treatment brings about its own problems, best seen in the examples of dyskinesia, off periods and impulse control disorders (Matson 2002; Weintraub *et al* 2013). Each man I interviewed took his own course through PD; his own symptoms moving at their own speed, causing its own issues based on men's individual contexts.

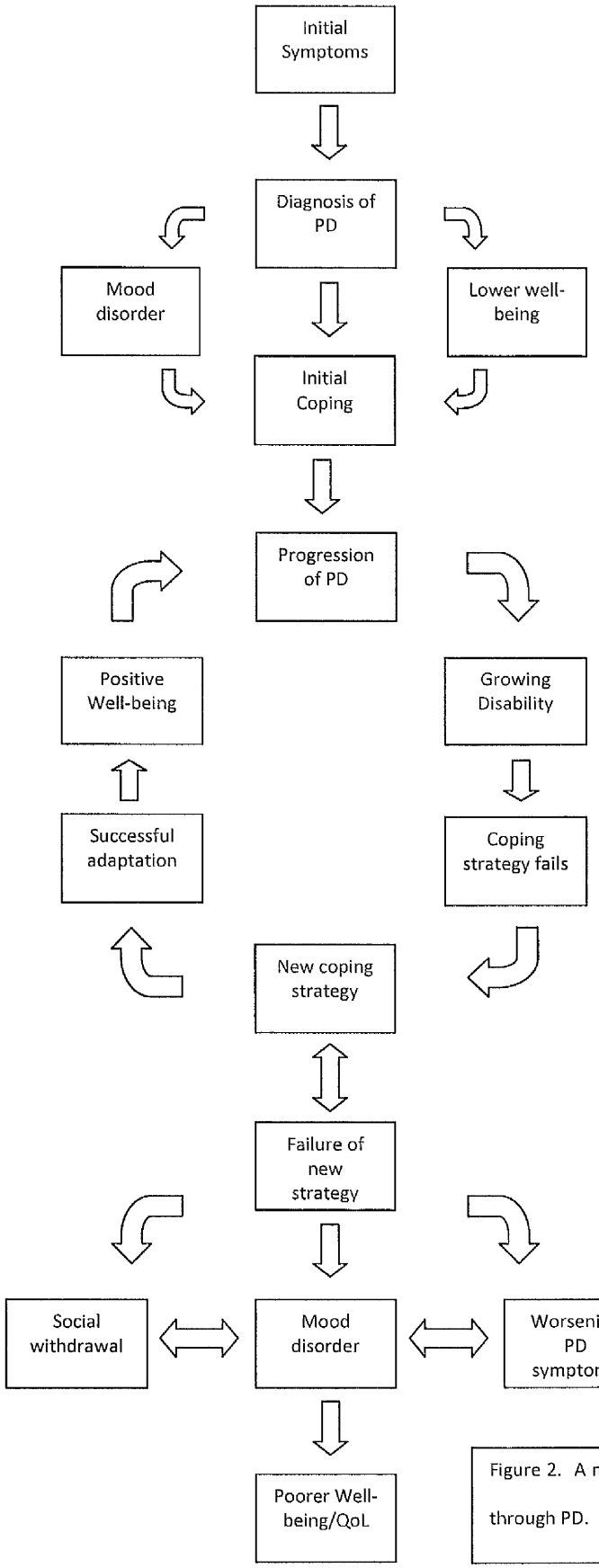


Figure 2. A model for men's journey through PD.

But men also experienced a number of similar concerns and issues, responding to PD in similar ways. Here I reflect on men's experiences of PD by drawing together a model characterising the journey men took through PD (fig 2). This model does not assume a simple linear progression in PD; of a deteriorating quality of life as PD worsens. Rather I show how men's experience of PD change as they move through their illness; as their PD worsens, as treatment brings benefits and as men learn how to deal with the problems PD causes. First I consider three distinct periods within men's journey through PD where medical interventions can assist in order to improve quality of life. After this I discuss how these interventions could potentially take place.

The diagnosis and early PD are the first point at which specific assistance and support can be provided. Upon diagnosis all the men I interviewed, to varying extents described experiencing a period which echoes Bury's (1982) seminal concept of biographic disruption, an *existential awakening;* characterised by shock, loss and their sudden awareness of the future and of death (Higgs & Rees Jones 2009; Bullington 2009). John, Albert, David and Harold claimed to shrug it off; for example by attributing PD to advancing age. Alternatively Bob, Roger, Simon and Dafydd felt deeply distressed, even suffering depression or anxiety as they struggled to come to terms with what PD meant for their lives. Many men noted a need or desire for support early in the disease, if not immediately at diagnosis then soon after; initially Dafydd 'didn't want to know' but soon changed his mind. Sooner or later men needed to incorporate PD into the biographical flow of their lives. It is therefore here that men noted a first period where timely assistance and support could be provided.

Secondly, little is static in PD. Men's orientation to their everyday activities continually had to change. But through these changes, men could develop a variety of means to responding to PD's effects; for example by seeking further information about the

illness; by what Dafydd described as 'learning to use the body in a different way'; or by changing the range of activities they continued to be involved with. It was here where men evolved a circular, iterative approach to coping with PD. Men found themselves having to revisit their approaches to their PD as their symptoms worsened and initial means of dealing with PD began to fail. This can most clearly be seen in the use of PD drugs. As PD's symptoms worsened medication regimens changed; dosages were increased and new medications added. Such changes invariably brought benefits, but would eventually be caught up by PD, once again needing further increases to dosage.

Men also faced similar problems in their wider lives. Instead of golf Henry and John played bowls. David took frequent rests during walks with his club, often curtailing his walks as he grew too tired, unable to keep pace with his friends. Hugh chose to sing in a less high profile local choir, to avoid the demands his previous choir placed upon him. Dafydd only drove for short distances. But all four men found these activities had to be continually revised. Henry found bowls was growing increasingly difficult. Dafydd struggled to drive even locally, driving was becoming just too demanding. David struggled with even short walks, quickly falling behind. All four had to consider giving these activities up. Men could make new meaning from their activities in order to sustain well-being, but this remained transitory, fragile, and vulnerable to the progression of their PD. Here is a further point for psychosocial interventions, assisting men in developing alternative ways of coping, and helping them to re-assess their activities and find alternative means either of expressing themselves or remaining engaged in their own social worlds. In doing so, PD's treatment can help to sustain men's quality of life and well-being as they move through the disease.

Over time most men found that the range of activities open to them gradually grew smaller and smaller. Men's spatial ranges shrank, while their ability to take part in

meaningful activities declined. Eventually even the most taken for granted activities; washing, dressing, eating or walking could become too much to manage. Some men found themselves struggling to cope with the demands of PD. Despite his PD being objectively measured as relatively mild, Ian struggled to cope with his PD symptoms. Ian's uncontrollable tremor meant he couldn't hold or move things easily. He struggled to manipulate even simple objects; screwdrivers, cups or kitchen tools. Those facing such difficulties were more likely to be unhappy, to experience low mood, or even exhibit symptoms of mood disorder; expressed as the consequence of their growing inability to cope with the demands of everyday life. Here therefore is a further period for intervention, assisting those who found themselves struggling to cope as their abilities declined; either by finding further ways to help them to maintain their independence, or alternatively helping them to manage the transition into greater forms of dependency.

Second, men's accounts of PD were spoken of in terms of its effects on their practical activities. Changes to these activities could be felt throughout men's lifeworlds. Men judgements about PD were based on its effects for these abilities and activities, rather than the objective severity of their symptoms. These activities therefore give a focal point for clinical practice to access PD's effects on men's lives, and how men make judgements about PD's effects and subsequently their own well-being. Greater attention should therefore be paid to PD effects on men's occupations and activities of daily living (Benharoch & Wiseman 2004). By doing so, clinical practice can better understand how men understand PD's effects on their lives, in relation to their sense of self as men, and on their quality of life and well-being.

Given men's focus on their accounts of occupations as a means to describe their lived experiences, there is scope for occupational therapy services to play a greater role in

PD's routine treatment. Occupational therapy already plays an important role in PD, for example through assessments of activities of daily living and through the use of a variety of occupational aids; walking frames, bed levers and a range of assistive technology devices (Gage & Storey 2004). However as noted in recent audits, such assessments do not routinely take place within PD services (Parkinson's UK 2011). As shown in this account, men's ability to continue with practical activities was central to their well-being, in particular demonstrating their ability to maintain a masculine sense of self. Therefore paying greater attention to assessments of activities of daily living in PD is important not only in terms of men's functional abilities, but also to men's wider well-being. Assisting men with such activities, and in particular the challenges men face in continuing with these activities throughout PD's course should therefore see greater attention both within PD research and routine clinical practice in PD (Elliot & Velde 2006).

Current clinical guidance in PD

It is also worth considering how far this thesis concurs with current recommendations for clinical practice in PD. It has long been argued that an inattention to individual experience continues to be a hallmark of PD research (Habermann 1999; Solimeo 2009; Stanley-Hermanns & Engbretson 2010). This is reflected in my literature review, where the claim that insufficient attention has been paid to PD's wider symptomology or to its impacts on quality of life features prominently across several literatures (e.g. Abudi *et al* 1997; Playfer 2007; Rahman *et al* 2008; Solimeo 2009). Although research into PD's subjective experience remains small scale, the research agenda in PD is beginning to pay greater attention to PD's wider effects. This widening of the research agenda is reflected in current clinical guidance for PD's treatment, issued by the National Institute for Clinical Excellence (NICE 2006). This guidance recommends a greater role

for multi-disciplinary practice in PD, however despite being introduced in 2006, there remain major challenges to the implementation of these services (Playfer 2007; APPGPD 2010; Parkinson's UK 2010; 2011). I therefore discuss how men's experiences of living with PD can inform current UK guidance for service delivery in PD. I focus on the four key areas highlighted within current NICE guidance for the treatment of PD; information provision, pharmacological treatment interventions, treatment of non-motor symptoms and non-pharmacological interventions (NICE 2006).

Information Provision

Found at the beginning of NICE guidance for PD's routine treatment, the timely provision of information appropriate to patient need is one of the major recommendations made for PD's treatment (NICE 2006; APPGPD 2009; Parkinson's UK 2011). However the timely provision of information about PD continues to be highlighted as a deficit in PD's mainstream treatment (APPGPD 2009; Parkinson's UK 2010; 2011). The men I interviewed frequently sought information about PD at diagnosis, and continued to seek information about PD as the disease progressed and new problems rose to the fore. However many also noted problems with accessing information within current services, including a lack of general availability, difficulties in contacting individuals and a lack of person centred information attuned to individual need. Given the importance of information provision as a tool in helping chronic illness sufferers to live with their condition, in this section I therefore discuss how, by reflecting on men's accounts of their experience, information provision to PD sufferers could be improved.

How can information provision therefore be improved in routine practice? Several questions arise, including how and when information should be provided, what should

be its content and who is best placed to provide it? First, when should information be given? People wanted information quickly, if not at diagnosis then soon after. But there are important caveats to giving men information at diagnosis. Medicine faces limits in the information it can provide. Many of the questions men asked about PD; why they had PD or how quickly they would deteriorate cannot currently be answered with any certainty, leaving several men looking to other sources. It is therefore important that when giving information, the limits both to medicine and to our wider knowledge of PD are clearly expressed. In addition, information was not universally positively received. Indeed it could potentially be damaging, leaving men potentially despondent about the future as they found that what medicine could do for them was ultimately limited. This research also indicates that information provision should be timely rather than early. Providing detailed information about problems several years down the line could be experienced as unhelpful or even distressing. However information needs also changed, people continued to want information even several years after diagnosis, with their needs changing according to their circumstances. Information provision must therefore be continual, tailored to individuals, their stage of the disease and their own individual issues. Any approaches to the provision of information for men with PD should therefore take these issues into account.

A further question is who should provide information to people with PD? Medicine was the central site where men expected such information and support to be readily available. But in practice, it was usually PD specialist nurses rather than consultants or other physicians that played the greatest role in supporting men's information needs. Hurwitz *et al* (2005) found that PD nurses have positive effects on patient well-being, in particular by acting as a bridge between senior clinical staff and patients. However more recently Axelrod *et al* (2010) argued that excessive workloads and wider resource

implications meant PD nurses were often unable to adequately perform their role. This finding was also borne out in this study. Where PD specialist nurses were available they were beneficial as first points of contact, or as information sources, easily contactable about a range of questions. However several noted no provision of PD nurse specialists, or alternatively experienced difficulties in contacting them. Where men felt they could easily contact PD nurses this had positive effects on well-being. But others noted that based on past difficulties they would only contact nurses in an emergency, diluting much of their role as a first point of contact. Therefore, the role of PD specialist nurses as sources of information provision is currently problematic (Axelrod *et al* 2010). If nurse specialists are to play a fuller role in PD services, including as key points of contact for patients, resource issues need to be addressed in order to ensure that they can play this role more fully, and that sufferers have adequate trust in their availability.

In practice, although most men spoke of medicine as their initial source of information, advocacy organisations, almost exclusively Parkinson's UK played the greatest role as a point of contact for information, advice and support. Most of the men had attended support groups at some point during their illness. However access to these services depended on their local availability. For some men, local groups were simply not available or were too difficult for them to reach. In addition some had little interest in the help they could give; Roger chose to avoid the company of others with PD despite its potential benefits, making him unwilling to attend his local groups. I therefore suggest that greater collaboration between clinicians and PD advocacy organisations at a local level is required in order to provide timely and appropriate access to information and support within routine clinical practice. Such links can reduce the demands placed on clinical services, while also ensuring that sufferers receive timely

and sympathetic information given by experts on PD's lived experience. Given the importance of information provision to sufferers knowledge about PD, and ultimately for their well-being, further attention should be paid to how information can be best provided.

Finally a question is what information should be provided. Men generally wanted information in two areas; to help them make sense of the existential questions arising in PD and to help them find ways to practically respond to its challenges (Habermann 1999). Examples included David's desire for information about when to move home, Simon's quest for methods to improve his own symptoms, or Albert seeking academic knowledge to explain the peculiarities of his own condition. Importantly, the range of information men wanted illustrated that their needs also evolved as men moved through the illness, changing as men found themselves facing new circumstances. At diagnosis concerns related to the existential shock of PD; why me, how did I get it, and what will happen to me in the future? Later on practical questions came to the fore; what can I do about it? How can medicine and its interventions help men to live more autonomously? What medical options would be available in the future? And what would their future care needs be? As PD progressed men also needed assistance with the transition to formal forms of support, when they should get it, how they should get it and what it would mean for them. Given PD's nature as a chronic, progressive illness, almost all sufferers will eventually need support with these concerns, but the accounts of the men I interviewed demonstrated that assistance with these issues was not routinely taking place. Many of these questions cannot be answered by medicine, but such are their importance to lived experience, helping men to negotiate the gaps existing in the range of information available to PD sufferers should also be considered.

In sum, more consideration needs to be paid into how, when, and by whom information provision in PD should take place.

Pharmacological treatment interventions

Drugs remain the primary therapy in PD, recognised within routine clinical practice and in sufferers own stories. Medication changes could have significant improvements both to physical functioning and quality of life. But they also led to numerous side effects which in the form of motor fluctuations and impulse control disorders can be more distressing that PD's underlying symptoms (Rahman *et al* 2008; Weintraub *et al* 2013). In addition, medication changes also possessed important symbolic meanings; used by men to mark their course through the disease and points of transition between the relative severity of their illness, for example Tony's account of the shrinking periods of time between disease, or Henry speaking of apomorphine as the 'end of the medication road'. Both these issues require consideration within the routine provision of PD therapy. Given such meanings, changes to medication could be approached with some trepidation; they were not simple events occurring within routine consultations. In routine practice clinicians should therefore consider the symbolic significance medications hold in sufferer's lives, and how this symbolism may affect the clinical encounter (Mattingly 1998).

In addition as noted throughout this thesis PD's medications brought about a number of further challenges. They do not return the body or the lifeworld to absence. Although bringing benefits to the body, they introduced a further structure to men's lifeworlds, one differing from their pre-illness experience. With medications a number of new embodied challenges grew, most saliently motor fluctuations and impulse control problems. Both these problems had dramatic negative effects on quality of life

and mood, both in the general PD population and among the men I interviewed. However few sufferers described openly discussing such issues with their clinicians. It was implicitly assumed by many that continuing with medications was the only option. Palliative concerns, for example about the withdrawal of medications should side effects become intolerable, or the range of problems that could occur in PD and what can be done to limit them were rarely considered, even for those facing these problems. How palliative forms of care can be provided in PD has seen relatively little consideration, but remains an important issue in future PD research (NICE 2006; Waldron *et al* 2013). Therefore greater attention needs to be paid to the lived effects of motor fluctuations, impulse control disorders and other medication induced side effects in PD. This is not just monitoring for their presence. Rather attention needs to be given to their experiential effects, how they are explained to patients, and how clinicians and patients together come to a judgement about how best to proceed with treatment. In doing so a greater degree of person centred care, attuned to individual experience and individual need can take place.

Treatment of non-motor symptoms

Increasing attention is being paid to PD's non motor symptoms, both in research and clinical practice (NICE 2006; Calne *et al* 2008). Men's accounts of PD prioritised motor symptomology, but several also noted PD's non motor symptoms. Of greatest significance were the frequent mood problems resulting from PD. Several men experienced depression or anxiety as part of their illness, either as a symptom or a consequence of PD's effects (Leentjens 2004). Relatively few of the men spoke openly of depression in terms of sadness. Instead it was more common for such problems to be described as being 'fed up', that they were losing interest in life around them or that being down was an understandable, natural consequence of their situations. Some

took antidepressants but denied they were for this purpose, instead stating they were 'calmers' or were taken to help them sleep. Only a few knew that depression and anxiety could actually be symptoms of PD. A combination of both lack of awareness of depression as a symptom of PD, alongside cultural discourses which discourage older men to talk about depression had implications for how likely men were to seek help (Emslie *et al* 2006; Thompson 2006). Further attention therefore needs to be paid to screening for depression in men with PD, to explaining its basis as a part of PD, and bridging the stigma existing around mental illness and older men. In addition, when men talked of mood problems, these were often located in their accounts of their functional problems, either as the cause or more often as a point of departure. Given the importance of occupations to men's accounts of PD, and as demonstrated by Ian and Bob, how talk of depression was based around men's accounts of these occupations, occupations provide an important avenue in which talk about mood problems can take place.

Several men also described experiences which were characteristic of impulse control disorder (Wu *et al* 2009; Weintraub *et al* 2013). Recent work by Weintraub *et al* (2013) indicates that these often distressing experiences are the result of PD's treatment, rather than being an inherent part of the illness. Commonly judged as being relatively infrequent, this study illustrates that although rarely seeking help for these problems, they could potentially be more common than is routinely judged in clinical practice. Based on clinical measures of severity many of the men's problems described in this thesis could be considered as 'mild', even sub-syndromal. However such a classification fails to acknowledge the significance of their lived experience, both for individuals and for their families who were often left to 'pick up the pieces' of men's impulsive or compulsive drives; (Roger's, Albert's and Henry's wives were worried

about their husband's impulsive activities, while Hugh's family had been forced to take over much of Hugh's financial responsibilities). Partners therefore were an important source of information, and were instrumental in monitoring these behaviours.

Complicating their being identified both by sufferers, carers or clinicians, impulsive experiences were usually interpreted via men's social expectations and social roles, giving men a means to explain them. However many men could assume they were exaggerated characteristics of masculine activity; what Henry described as 'doing too much', about buying or driving cars (Roger), gambling and spending large amounts of money (Albert, Hugh, Henry) or sexuality (Albert). These cases were relatively minor and therefore may not be picked up by clinicians, but were still highly distressing for both patient and family. Few options are currently available to help with impulse control disorders (Weintraub *et al* 2013). Generally the only option described by men was to reduce medications, leaving men with little option but to 'grin and bear it'. Simply knowing of the presence of impulse control disorders made them easier to manage but did not eliminate them; the men still had to deal with their various, alien desires, often with little support from family. Given the sometimes severe distress that impulse control disorders can cause here we therefore see a specific need for clinical and psychological intervention, helping sufferers to best manage these often distressing experiences. There is a need for further research to take place investigate in what form such interventions could take place, but undoubtedly when such problems do occur, greater attention needs to be paid to how they can be successfully managed.

Non pharmacological interventions

Non pharmacological interventions, such as those provided by occupational therapy, physiotherapy, speech and language therapy or psychological therapies all have

increasing roles to play in the routine treatment of PD (Benharoch & Wiseman 2004; Van Der Marck *et al* 2009). Most of the men I interviewed had some experience of non-pharmacological treatments, most commonly physiotherapy or assistive devices provided by occupational therapy (bed levers, handrails etc.). A few men, including Phillip had also received speech therapy in order to improve the volume and clarity of their voice. However few discussed these interventions in any great detail. It was not that non-pharmacological interventions were not routinely available, although in some localities this was indeed a problem. Rather drugs remained the central intervention in men's lives, shaping men's judgments about the benefits, and in some cases even the point of non-pharmacological services. Several prioritised drugs in their accounts of treatment, noting that despite being given exercises to promote continued functioning (for example vocal exercises to promote volume and clarity of speech or physical exercises to sustain flexibility), few followed these exercises in any sustained way. Men either failed to engage with them in a sustained way or in Simon and Albert's case preferred to use their own methods.

When recommending non-pharmacological therapies requiring sustained effort from patients, for example physiotherapeutic or vocal exercises, greater attention needs to be given to how adherence can be improved, particular when they, unlike medications, failed to give immediate or obvious benefits. Those who did engage with them highlighted benefits beyond their clinical narratives. Two examples give clues as to potential ways in the use of non-pharmacological interventions could be promoted; Simon's use of the Nintendo Wii video games console, and Harold's talk of his physiotherapy sessions as a 'gym'. In both these examples the therapeutic benefits were often secondary to more immediate social experiences. For Harold the 'gym' was a social space, where he could engage in masculine forms of friendships based around

physical activity, rather than a site for the treatment of his PD. For Simon, the Wii was a form of interactive entertainment. But more important, through using the Wii, Simon could turn the monitoring of his symptoms into a 'game', trying to improve his score and by proxy improve his body. Through both examples Simon and Harold derived new meanings from these activities, both of which improved their adherence to these 'treatments'. Through such innovative approaches to non-pharmacological interventions, attuned to how they are followed within men's own contextual situations, it is possible that adherence to these therapies could be improved. Given their importance, how non pharmacological therapies can best be implemented is an area where further research would be beneficial (Van Der Marck *et al* 2009).

Finally psychological therapies are gaining increasing attention within PD, albeit from a low base (e.g. Gage & Storey 2004; Simpson *et al* 2006; Dobkin *et al* 2007). Given the broad prevalence of depression and anxiety in depression, there is significant need for services in this area (Brown *et al* 2011). Psychological therapies could have great usefulness in treating mood disorders in PD, and also in assisting sufferers to adopt what have been considered to be beneficial coping strategies (Hurt *et al* 2011). In addition such approaches could also help men to deal with the consequences of impulse control disorder without reducing PD medications. But on the ground such services remain rare. Despite their potential benefits across many aspects of PD's lived experience, psychological therapies did not appear to be routinely available as an integrated part of PD care for any of the men I interviewed. More routinely, those with mood problems were usually prescribed anti-depressants. Such prescribing was done according to guidance for the treatment of depression rather than the specific treatment of depression in PD (NICE 2006). Although few were willing to initially admit or discuss mood problems, many of these men did discuss a need for such services.

There is therefore a need for further research into how such services could best be implemented, which approaches are most beneficial in PD, and how psychological therapies could provide important tools in assisting in particular aspects of PD's experience; including impulse control disorders and coping strategies in addition to mood disorders.

Summary

In this thesis I have explored men's experiences of living with PD, the challenges they face, and their experiences of medicine and its treatment in PD. Highlighted throughout this thesis has been the issue that, in prioritising a neurological and pharmacological approach to PD, less attention has been paid to PD's phenomenological experience, how these experiences inform men's social roles, for example within the household, and ultimately how these experiences can inform patient care (Habermann 1996; Bramley & Eatough 2005; Solimeo 2008). By addressing such issues, clinical care can better address the lived concerns faced by men with PD, thereby improving quality of life and well-being for the group making up the majority of PD patients (Haaxma *et al* 2007).

Part 3. Reflections on the research

This study has given us key insights into PD's lived experience; the problems it causes for men's lives, how men deal with the effects of their illness, and the role that gender and ageing play in men's understandings of their own individual PD. But as with any research endeavour, it is important to reflect on its conduct; what went well, what went poorly and what lessons can be learned for future research. To bring my thesis to a close, I discuss some of these reflections, what I feel are the limitations of this study,

and the important directions for future research in PD and its subjective experience raised by this study.

Limitations of this research.

There are a number of limitations and difficulties which must also be considered when discussing the results of this thesis, and when using them in improving services. Here I discuss some of these issues.

Sampling framework

Large samples are not necessary in phenomenology; indeed large sample sizes preclude the detailed investigation of lived experience characteristic of phenomenological inquiry (Benner 1994; Carel 2011). But sample size remains an important question. Rather than considering statistical generalisability we must consider questions of validity, whether a study captures the full range of lived experiences in its subject of interest (Denzin & Lincoln 2011). It is here where I first indicate some of the limitations arising in this work.

First, although I designed the sampling frame to access as wide a range of experiences as possible, there were important groups of men who were under-represented in my sample. My sample was derived from participants in the PROMS-PD study. Doing so gave me access to detailed information about a wide group of PD sufferers, but also restricted my ability to access some groups of men. None of the men in this study had what is defined as young onset PD, below the age of 40 (Schrag 1998; Calne *et al* 2008). None of the men were aged below 50 at interview, while only Roger had young onset PD at diagnosis. Local service designs meant young onset patients were routinely referred to neurological services which were not part of local recruitment for PROMS-

PD. When this study was initially designed it was expected that PROMS-PD would give a sufficient number of young onset sufferers, however at recruitment only one (Roger) accepted. Others declined due to their poor health, or dropped out of PROMS-PD before recruitment into this study began. Given these limitations, the lived experiences of younger onset PD sufferers remain an important opportunity for future PD research (Schrag *et al* 2003).

Secondly, accessing both newly diagnosed patients and those with later PD also proved difficult. Because PROMS-PD was into its third year when I conducted these interviews, I could not interview any men who were newly diagnosed. All men had been diagnosed at least three years earlier. In building my sampling framework, I endeavoured to include patients who were diagnosed at the beginning of PROMS-PD; examples included Simon, John, Harold and Peter. But not being able to interview newly diagnosed sufferers shaped the data I collected and its findings. Many of the men described diagnosis, but these were not current experiences. Instead diagnosis was interpreted through the selective recall of memory (Good 1994; Mattingly 1998). This is a strength of narrative, but of course means that accounts of the immediate experience of diagnosis were absent. This must be remembered within my wider discussion.

Accessing those in the most severe stages of neurological illness has proved extremely difficult across research in this area (Wilkinson 2002; Gibson *et al* 2004). No men at Hoehn & Yahr stage 5, the most severe stage of PD (*'wheelchair bound or bedridden unless aided')* could be recruited (Hoehn & Yahr 1967). Indeed those at this stage usually dropped out of PROMS-PD; they were no longer able to cope with the demands of the research. For those with the most severe form of PD mobility is just one of a whole range of problems including severe cognitive decline, mood disorder and even

loss of the ability to speak. Given the often severe impairments faced in later PD, it is easy to assume that those at this stage will have a poor quality of life and a higher likelihood of mood disorder (Schrag 2006). However this is not inevitable; as Schrag *et al* (2007) indicates, they could also gain meaning and positivity out of life even in severe PD. It is therefore important for us to gain perspectives of those at later stages of PD; their lived experiences and how they respond to PD's often severe effects. Some work in this area has taken place; for example Haahr *et al* (2010; 2011) and their study of PD's lived experience after deep brain stimulation. In addition, through innovative qualitative research designs such as ethnography, or the observational approaches adopted in the study of dementia (e.g. Kitwood 1997; Woods 2001; Wilkinson 2002; Innes *et al* 2012) we can access their experiences. If we wish to explore the care needs and experiences of those with severe PD, innovative approaches involving the cross fertilisation of ideas from the study of other illnesses, or even of other disciplines is required.

Limitations & reflection on my study methodology

Narrative methodology proved to be a particular strength in this study. But narrative can also be a particularly challenging form of research, requiring a change of mindset for both interviewer and participants. Although experienced in both qualitative and clinical interviewing prior to this study, this was my first experience of using narrative methodologies. I therefore reflect on some of the challenges I faced using narrative methods. One of the greatest strengths of this research was the prior contact and rapport I had built up with the men of this study, a rapport that enabled the collection of empirically rich descriptions of often very intimate lived experiences. But this prior contact did have important practical and methodological implications. Not least, my

use of narrative interviewing needed an entirely different orientation by both myself and for the men I interviewed.

Second, the ability of the men I interviewed to recount their stories in the form of narratives are likely to have been influenced by the nature of our prior contact. In our previous contact as part of PROMS-PD I asked the men lots of clinical questions, seeking brief, often yes/no answers using pre-determined, validated interview schedule. During these earlier interviews men often tried to answer questions by telling stories, but the practicalities of clinical interviewing meant such narratives had to be quickly (but sensitively) shut down. My narrative interviews required a re-casting of roles. I had to explain that I was now seeking a different form of data from participants, and that it was now their role was to lead the interview; to go where they chose rather than just answer my questions in a staccato fashion. But I also had to learn to let them do this; to not cut them off, not to focus on issues of interest to me. In addition I had to resist helping men to speak as they struggled to construct their thoughts or complete their sentences. This was exacerbated by PD, which could often make it easy to lose the flow of a conversation, or make it difficult for men to find the right words (known in PD as the 'tip of the tongue phenomenon').

Moreover, my prior knowledge of the men also influenced my openness to the stories they told. I knew these men well, having visited them many times over three years. I also knew their symptoms and problems, and I also knew several of the men's stories well. I chose during the first year of PROMS-PD interviews to explicitly listen to men's stories even where they diverged from the goals of PROMS-PD, a choice made in order to familiarise myself with the worlds of PD sufferers. This was particularly useful in helping me develop a maximum diversity sample. But it did cause problems. Having heard men's stories before, I had several moments where I lost sight of some of the

most basic bodily experiences occurring in PD. I tried to counter this, for example by revisiting field notes and quantitative data collected within the PROMS-PD study, through my first experiences of interviewing people with PD, and through discussions with supervisors, with other postgraduate students, and of course with the men with PD themselves. In addition, in a form of member checking, I returned copies of transcripts and photographs to participants, inviting them to make any comments or amendments. Relatively few responded, but those that did made interesting comments which further informed my thinking. Through this approach, I managed to bring this account of PD together.

Several of the men I interviewed struggled to discuss their experiences in the form of stories. It is a cliché, but not entirely a false one, that men are unwilling to discuss their feelings (Oliffe & Mroz 2005; Oliffe & Bottorff 2007). I found most of the men were willing to open their emotional worlds up to my inquiries; however they did so through talk of their practical activities. Such talk reflects Laz (2003) argument that an ageing embodiment is an accomplishment; something men 'do' and express through their everyday acts. Rather than men talking about such experiences as a means to avoid emotional expression, I found that men's emotional experiences were expressed through these acts; an important issue when considering how to discuss emotional issues such as mood disorders with men. This is an important outcome of this study, but requires attention when designing research on often emotionally sensitive issues with men (Oliffe & Bottorff 2007). Finally, in a related issue, in this study I sought to consider both the content of men's stories and their emplotment; the resource men use in the telling of their stories. Given the broad remit of this study; concerned with men's lifeworlds; there is further scope for deeper narrative approaches to explore PD; for example studies engaging with the use of language as a means of describing PD,

and how this use reflects wider social discourses; for example around medicine and its role in defining illness in older age. Pickard (2010) and Pickard & Rogers (2012) illustrate the utility of such an approach in the study of illness in older age. Further research drawing upon this study could further explicate these issues.

Reflections of the use of photo elicitation methods

Here I discuss some of my reflections of the use of photo elicitations methods in this study, how it helped in my thinking, how I used this method, and the problems I faced in its use. Photo elicitation methods have proved to be a useful and creative approach in helping us to access experience of illness (Oliffe & Bottorff 2007). In addition, designing multiple research methods, data collection and analytical techniques can often provide interesting and often more detailed insights than one method alone. But it also creates extra demands and extra problems; not least how to combine visual and interview based data sources at the stages of planning, data collection, analysis and writing up.

Perhaps the most significant issue I faced was how to integrate visual research within my phenomenological, narrative methodology. My original goal was to encourage men to use photographs as a reflective exercise, to think about just how far PD had changed their lives. However in practice I found that men most often used photographs to reinforce their earlier accounts of PD. Doing so provided an important aid to storytelling; illustrating the power of these experiences. But importantly men also used these photographs to position themselves in relation to the stories they were telling. Two issues featured most prominently. First, the men themselves featured heavily in the photographs they took. Many of these photographs, taken by family on their request, were used to provide evidence of what they could still do. Men featured

in various forms of acts, from engaging in sports, to gardening, to driving, to simply making a sandwich. Few photographs simply focused on illustrating the problems they faced; they usually also had the further goal of showing what they could achieve. This moves on to a second point, that the majority of photographs focused on men's accomplishments. All these acts, many of which were previously easily achieved, were now effortful accomplishments. But by talking of the effort required, but also their success, men could reinforce a masculine presence within their worlds. Through men's photographs then, they reinforced a central theme of their narratives, that by showing just how active they remained, they could reassert a masculine presence within the world, even reinforcing their own sense of masculinity. This was undoubtedly a strength of this approach, yet requires a way of reading photographs, based on how they are used in conjunction with stories in addition to their content.

I also faced a number of practical problems which are worth reflecting on. First it was difficult to communicate the purposes of the photographic elicitation exercise. Several struggled to decide what photographs to take. Only 9 of the 15 men took part in the photo elicitation exercise. Several forgot, a practical but important issue. But more commonly, some of the men were either unable to decide what to take, or felt that their experiences were not worth recording. Some men needed extra support, but I found this could also influence the photos they took. For example, after giving examples of what I wanted them to take, Bob and Tom simply reproduced these examples. After this I found I had to think more flexibly about describing this approach. Photographic elicitation methods are a useful tool in encouraging participants to be reflexive. But how it is explained needs careful consideration.

Finally it is worth considering how I integrated the photographic data into my wider analysis. The above use of photographs was different to my original expectations and

original goals, requiring me to rethink how I would use this data and integrate it into my wider analysis. I chose to use photographs in much the same way as men did, to reinforce the stories they told, and therefore to show the significance of these various acts of doing to a masculine embodiment. This did mean that I focused in greater detail on the content of men's photographs rather than their nature as an emplotted form of data; the questions of how and why they took these particular photographs, and the various issues that men either neglected to photograph, or even chose not to photograph. Such issues raise interesting questions, which are not adequately addressed within this thesis. In conclusion, I found photo elicitation methods to be a useful and beneficial method to use in combination with phenomenological narratives. However, in order to achieve its full potential, participants and researchers must be committed to its use and to the goals it seeks to achieve (Oliffe & Bottorff 2007). In addition flexibility must be adopted as, when people are given the freedom to collect data as they see fit, they will invariably do so in ways not expected at the onset of a study. By taking account of these goals, photographic elicitation is a technique that has further utility for research with older men; further methodologically informed research could further investigate how such methods can inform our knowledge of the socially situated nature of ageing.

Concluding comments

This study has explored the phenomenological lifeworlds of men suffering from PD. PD is an illness which fundamentally affects the inter-relationship of the body, self and world, leaving few elements of sufferer's lives untouched (Bramley & Eatough 2005). In order to provide holistic, person centred treatment interventions more appropriately addressing sufferer's needs, clinical practices must be more closely attuned to these experiences. The study of men's lifeworlds in PD also gives us key

insights into how PD as an illness is produced through wider social discourses, including ageing, gender and the practices of medicine. Through a consideration of PD we reveal how gender remains a salient experience in the lives of older men, shaping both how PD is produced as a problem in men's lives, and how they should respond. Taking such a position informs our knowledge of PD's treatment practice, therefore giving us the means to intervene with PD's lived experience. In doing so, we can promote greater well-being; helping sufferer's in the face of this debilitating disease.

Chapter 10. Bibliography

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Appendix 1. Sampling framework.

ID	Location	Characteristics	ID	Location	Characteristics	ID	Location	Characteristics	ID	Location	Characteristics
3001	NW	O, S	3061	W	N/A	3114	NW	O, S, Dep	3160	NW	O, M
3002	NW	O, M, Dep	3065	W	O, M	3115	NW	O, M	3161	NW	N/A
3004	NW	O, M	3066	W	Y, S, Dep, On	3118	NW	O, M	3164	M	O, M
3006	NW	Y, S, Dep, on	3067	W	O, M, On	3119	NW	O, S, On	3165	NW	O, S, Dep
3009	NW	O, M	3068	W	O, M	3120	NW	O, S	3167	NW	Y, S, Dep, On
3010	NW	O, M	3069	W	O, M, On	3121	W	O, M, Dep	3172	W	O, M
3012	NW	O, M	3072	NW	O,M	3122	W	N/A	3174	M	O, S
3013	NW	Y, M, Dep	3075	M	O, S, Dep	3124	NW	O, M	3175	M	N/A
3015	NW	O, M, Dep	3078	NW	O, S, Dep, On	3127	W	Y, M,	3179	NW	O, M, dep
3017	NW	O, S	3081	NW	N/A	3128	NW	Y, M	3181	NW	O, M, dep
3022	NW	O, M, dep	3082	W	O, S	3129	NW	O, M	3182	NW	O, M
3023	NW	O, M, On	3084	W	O, M, Dep	3134	NW	O, M	3183	NW	O, M

3027	NW	Y, M	3087	NW	O, M	3135	NW	O, S, On	3184	W	N/A
3028	NW	O, S	3093	W	N/A	3136	W	O, S, On	3185	NW	O, M
3029	NW	Y, M, Dep, On	3094	W	O, M	3137	W	O, M, Dep, On	3186	NW	O, M
3030	NW	O, S, On	3097	NW	O, S, dep, on, cog	3138	M	O, M, Dep, On	3148	NW	O, M
3036	NW	Y, M	3098	NW	O, M	3139	NW	O, M			
3037	NW	O, M	3099	NW	O, S, Dep	3141	NW	O, M, On, Cog			
3040	NW	O, M	3100	M	O, M,	3146	NW	O, S, Dep, On			
3042	M	O, S	3101	M	O, M, Dep	3147	W	O, S			
3045	NW	O, M	3103	NW	Y, M	3149	M	O, M,			
3046	NW	O, S, Dep	3104	NW	Y, M	3151	W	O, S			
3049	M	O M, Dep	3106	NW	O, M	3152	W	O, M, On			
3051	NW	N/A	3107	NW	N/A	3153	W	O, M			
3054	NW	O, M	3109	W	O, M	3154	W	O, S			
3057	M	O, M, On, Cog	3110	NW	Y, M	3155	W	O, M, Dep			

Key.

W: Wirral
M: Merseyside
NW: North Wales

Y: PD onset <65
O: PD onset> 65
M: Mild PD
S: Moderate/Severe PD
On: motor fluctuations
Dep: mood disorders
Cog: Cognitive impairment

Final Sample highlighted

3058	NW	O, M, Dep, cog	3112	NW	O, M	3156	M	N/A
3060	W	O, S	3113	NW	N/A	3159	W	O, M, Dep

Appendix 2. Information Sheets and Consent forms

Contents.

Appendix 2.1 Participant invitation letter

(NHS letter head)

Patient Address

Dear Mr ...

I am writing to you to invite you to take part in a research study. I am contacting you because you are currently taking part in the PROMS PD research study, and have agreed to be contacted to take part in other research projects connected to the PROMS PD study. This project seeks to men's experiences of living with Parkinson's Disease and the problems it causes for everyday life.

If you agree to take part, I will conduct two interviews with you. During each interview I will ask you some questions about your Parkinson's disease, and the impact that Parkinson's disease has on your everyday life. Between the two interviews, I may also ask you to take some photographs of elements of your life which are affected by your Parkinson's disease.

I have included an information sheet with this letter, containing further details about this study. Please read the information sheet included with this letter. I will contact you via telephone within the next week, and try to answer any questions that you may have. You are free to choose whether or not to take part in this study.

If you have any questions or concerns, please contact me at 0151 604 7333.

Yours Sincerely

Grant Gibson
Research Assistant: PROMS PD.

Invitation letter v1.0. 23/06/2008

Appendix 2.2 Invitation letter from PROMS-PD Study Co-ordinator

ıstitute of sychiatry

The Maudsley

Department of Psychology, PO77
Institute of Psychiatry
De Crespigny Park
London SE5 8AF

Dr Catherine Hurt
PROMS-PD Study Coordinator

Tel: 020 7848 0923
Fax: 020 7848 5006
Email: Catherine.hurt@iop.kcl.ac.uk

KING'S College LONDON

University of London

<date>

Dear <participant name>

PROMS-PD Supplementary Study

I would like to take this opportunity thank you for giving up your time for the PROMS-PD study. When you first agreed to take part you indicated that you would not mind being contacted about other related research studies.

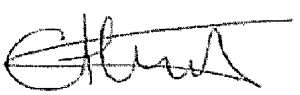
Enclosed with this letter is some information about one such study, titled 'Men's experiences of living with Parkinson's Disease'. This is being carried out by Grant Gibson from The University of Liverpool, and has been approved by the PROMS-PD Management Group. Grant has been provided only with your name and contact details.

The accompanying letter tells you some more about the new study. As it explains, you are free to choose whether or not to take part. If you choose not to take part in the new study, you will still be in PROMS-PD. If you would rather not be contacted about additional research in the future please let me know so that I can make a note on our records.

If you have any questions about the new study, you should contact Grant Gibson directly on the number given on the attached letter. If you have any questions about PROMS-PD please contact me on 0207 848 0923 or Catherine.hurt@iop.kcl.ac.uk.

Thank you once again for your help with our research.

With thanks and best wishes



Dr Catherine Hurt
PROMS-PD Study Coordinator

Appendix 2.3. Letter sent to GP informing them of participant involvement

(NHS Trust Letterhead)

Dr Address

Dear Dr ...

Men's experiences of living with Parkinson's Disease: A PROMS PD bolt on study

I am writing to inform you that your patient is currently taking part in the above research study:

Name: ...
Address: ...
Date of Birth: ...

This is a research study examining men's experiences of living with Parkinson's Disease. A copy of the information sheet is included with this letter. This is not a drug trial and will not affect your patient's care in any way. If you would like a copy of the protocol please do not hesitate to contact Grant Gibson on 0151 604 7333.

We will notify you of any clinically relevant information which may arise as a result of your patient participating in the project.

If you have any questions regarding this study, or know any reasons why the patient should not be involved in the study, please do not hesitate to contact me on 0151 604 7333.

Yours sincerely,

Grant Gibson
Researcher

Appendix 2.4 Participant information leaflet

(NHS trust Letterhead)

Patient Information Sheet
(version 1.2. 18/09/2008)

Studying men's experiences of living with Parkinson's Disease

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Part 1

Invitation

You are being invited to take part in a research study. Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives or your doctor if you wish.

- Part 1 tells you the why this study is being carried out and what will happen to you if you take part.
- Part 2 gives you more detailed information about the study.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. You will find out contact details at the end of this sheet. Thank you for reading this. In a day or two, someone from the research team will telephone to talk about the study and see if you are interested in taking part.

What is the purpose of the study?

Men suffering from Parkinson's disease can experience a wide range of problems as a result of the condition, or as part of its treatment. Some of these problems, such as difficulties with movement, may affect an individual's ability to go outside, to walk around, or to take part in a lot of activities that other people may take for granted. In particular, Parkinson's disease may affect the range of activities they can take part in at home, such as cooking or cleaning. These problems might affect how men with the disease feel about different aspects of their lives, and the places in which they live. Finally, for some men, having a disease like Parkinson's disease might also affect how they feel about themselves as men, and the type of roles that a man is expected to play in everyday life. Although we know a lot about the medical problems caused by Parkinson's disease, we know less about how these problems might the everyday lives of men with the disease. This project hopes to provide more information on the ways in which Parkinson's disease can affect the everyday lives of those living with the disease, by understanding how it affects peoples activities within their everyday environments.

Why have I been chosen?

You have been invited to participate in the study because you have been diagnosed with Parkinson's disease; you are currently taking part in the PROMS PD research study, and have agreed to be approached about taking part in other studies connected to the PROMS PD study.

Do I have to take part?

No. It is up to you to decide whether to take part. After you have had some time to read this, we will contact you by telephone and try to answer any questions to help you decide. If you choose to take part, you will keep a copy of this information sheet and we will ask you to sign a consent form. You are still free to withdraw at any time and without giving a reason. If you decide to withdraw, or not to take part, it will not affect the standard of care you receive.

What will happen to me if I take part?

We will arrange a convenient time to visit you at home, or to see you in the hospital, which ever you prefer. If you decide to come to the hospital, we will pay your travel costs. You can have a friend or family member with you if you wish.

The researcher will see you on two occasions. Each visit will last no more than one and a half hours (with breaks) and will probably be much shorter. You can also choose to only take part in one interview if you prefer.

During each visit, you will take part in an interview. During the first interview, you will be asked to talk about your experience of having Parkinson's disease. You will also be asked about the kind of impact that Parkinson's disease has on your everyday life, activities and on any other aspects of your life that are important to you. The researcher will then document those issues that are important to you.

The researcher will also give you a disposable camera and give you the choice to take some photographs of your home and other aspects of your everyday life that are affected by your Parkinson's disease. Previous research has shown that talking about photographs can help people to think about some of the issues affecting them. These photographs will be used for research purposes. With your permission, they may also be used in reports and in future journal articles and other publications. Any information that could be used to identify you will be removed. You do not have to take any photographs if you do not want to. Photographs will be destroyed at the end of the project.

During the second interview, you will be asked to talk about the importance of any photographs that you took. You will also be asked to talk further about the issues you mentioned during the first interview. More details are given in Part 2. With your permission, both of the interviews will be tape recorded.

If you give your permission, information collected about you and your Parkinson's disease as part of the PROMS PD study will also be used in this study. This data will be used to provide information on some of the problems or symptoms you may be suffering from that are associated with Parkinson's disease, and the severity of these problems.

If you give your permission we will also let your GP know that you are taking part in this study. We will also let your GP and hospital doctor know if we find out important new medical information so that they can take any necessary action.

No new drugs are involved in this study. It is not a drug trial.

What do I have to do?

The researcher will contact you to arrange to visit you at home, or for you to attend the clinic. If you wear glasses or use a hearing aid, we ask that you have these with you, as you will need them during the interview. You will be able to take your normal medication as prescribed by your doctor.

What are the possible disadvantages and risks of taking part?

The study does not interfere with your treatment, therefore it is unlikely that you will experience any harm by taking part in the study. If you do find that taking part causes you any discomfort, distress or concern you are free to stop or withdraw at any time.

What are the possible benefits of taking part?

While there are no immediate benefits in taking part in this study to you personally, we believe that the information gained will improve our knowledge of Parkinson's disease. The information is of great potential benefit to future patients with Parkinson's disease. We also hope that you will find it interesting to take part and learn of the results.

What if there is a problem?

You should let us know if you have any complaint about the study or feel that you have suffered harm. You can find more information in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will keep all information strictly confidential. Only you and members of the research team will know that you are taking part in this study. You can find more details in Part 2.

With your consent photographs recorded during the study may be used for illustration purposes in reports and any subsequent journal articles. This may mean that your anonymity cannot be guaranteed. Where possible your permission will be sought for the use of photographs in any future publications

Contact Details:

If you, your family or your carers have any questions about the study, or if you have any concerns during the study, please do not hesitate to contact:

Grant Gibson. Tel 0151 604 7333 ext 3726

If no one is available please leave your details on the answer machine and we will return your call as quickly as we can.

You can write to me at:
Grant Gibson
Academic EMI Unit

University of Liverpool
St Catherine's Hospital
Church Road
Birkenhead
Wirral
CH42 0LQ

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and think that you might like to take be involved, please continue to read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

Once you have agreed to take part in the study you may decide that you do not wish to continue. You are free to withdraw at any time without giving a reason. This will not affect any of your routine care at hospital or from your own doctor. If you decide to withdraw, we will ask your permission to keep the information that we have already collected.

What if there is a problem?
Complaints:

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. You can obtain details from the hospital.

Harm:

In the event that something does go wrong and you suffer harm during the research study, there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against (NHS trust) but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

If you feel that you need any medical care as a result of your participation in this study, you can contact the consultant providing you with your care at (Dr John Hindle (Wales), Dr Glyn Scott (Liverpool) or Dr Chris Turnbull (Wirral)) (Address), or contact (Prof Ken Wilson; educational supervisor & consultant psychiatrist), who will put you in contact with your care team.

Will my taking part in this study be kept confidential?

All the information you provide during the course of the research will be kept confidential. It will be securely stored in locked files or a secure computer database. Only authorised individuals directly involved with the study will have access to the information obtained.

We will use a unique number on all records, rather than your own name. Your personal details including your name and address will be stored separately in a secure place. Only you, your own GP and hospital doctor, and the researchers will know about your involvement in the study. With your agreement, members of your family or a carer may be asked for help in answering some of the questions.

After the study has ended, we will keep the information for at least 15 years. After this time, it will be disposed of securely. The procedures for handling, processing, storage and destruction of the data are compliant with the Data Protection Act 1998.

What will happen to the results of the research study?

We will use information from the study in presentations or published in scientific reports. These will not identify any individual taking part. You will be sent a full summary of the results at the end of the study.

Who is organising and funding the research?

The study is being organised by the University of Liverpool. This study is taking place as part of a PhD study being undertaken by the chief investigator, as part of the PROMS PD research study.

Who has reviewed the study?

The study has been reviewed and given a favourable ethical opinion for conduct in the NHS by the South Manchester Research Ethics Committee.

Can I take part in other studies?

This project is part of the PROMS PD research study. You may also be asked to take part in future research studies that are also part of the PROMS PD study._You are free to take part in any other study if you wish.

Thank you for considering taking part and taking time to read this sheet.

Appendix 2.5. Consent form

(NHS Trust Letterhead)

Centre Number | | Patient Identification Number for this study | |

CONSENT FORM
(version 1.3 23/09/2008)

Men's Experiences of Living with Parkinson's Disease

Name of Researcher: Grant Gibson

Please initial box

1 I confirm that I have read and understand the information sheet dated 18/09/08 (version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |

2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. | |

3 If important medical information is found as a result of my participation in this study, I agree that the research team may inform my GP or consultant about this. | |

4 I agreed to my being tape recorded, and my comments being used as quotations in the study. My name will be removed from any quotations. | |

5 I understand and agree to photographs being used for research purposes. No photographs will be published without my prior consent. As far as possible any identifying information will be removed, however this cannot be guaranteed. Photographs will be destroyed after the end of the project. | |

6 I agree to the researcher accessing limited information about me and my Parkinson's Disease symptoms collected as part of the PROMS PD study. | |

7 I agree to my GP being informed of my participation in the study. ☐

8 I agree to take part in the above study. ☐

Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

Appendix 2.6. Approval letter from Greater Manchester South Ethics Committee

NHS

National Research Ethics Service

North West 6 Research Ethics Committee – Greater Manchester South
Northwest Centre for Research Ethics Committees
3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7816

26 November 2010

Private & Confidential
Mr G Gibson
Research Assistant
University of Liverpool
Academic EMI Unit
St Catherine's Hospital
Birkenhead
CH42 0LQ

Dear Mr Gibson

Study title: **Experience of Place amongst men suffering from Parkinson's Disease**
REC reference: **08/H1003/131**

This study was given a favourable ethical opinion by the Committee on 30 September 2008.

It is a condition of approval by the Research Ethics Committee that the Chief Investigator should submit a progress report for the study 12 months after the date on which the favourable opinion was given, and then annually thereafter. To date, the Committee has not yet received the annual progress report for the study, which was due on 01 October 2009. It would be appreciated if you could complete and submit the report by no later than 29 December 2010.

Guidance on progress reports and a copy of the standard NRES progress report form is available from the National Research Ethics Service website.

The NRES website also provides guidance on declaring the end of the study.

08/H1003/131:	**Please quote this number on all correspondence**

Yours sincerely

Miss Diane Catterall
Assistant Committee Co-ordinator E-mail: diane.catterall@northwest.nhs.uk

Copy to: Lindsay Carter
Research Co-ordinator
Faculty of Health & Life Sciences
University of Liverpool
1st Floor, Duncan Building
Daulby Street
Liverpool
L69 3GA

This Research Ethics Committee is an advisory committee to North West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix 3. Data analysis process

Appendix 3.1 Data Management and analysis procedure	
Analysis Stage	Method
1. Narrative interview	• Narrative interview conducted in participants own home. Based on BNIM (Wengraf) • Field notes of main points of interview, issues of discussion, particular points/events of interest, and reflective thoughts of interview process recorded immediately after interview. • Field notes recorded on tape immediately after interview and later transcribed
2. Narrative interview analysis	• Interview transcribed ASAP after narrative interview. • Read through transcript from start to finish to gain overall summary of interview. • Line by line coding of each page of transcript. • Initial themes noted in margins of transcripts • Initial themes used to generate further issues for enquiry in semi structured interview. Individualised follow up interview schedule generated from themes based around lifeworld existentials, gender and ageing.
3. Photographs	• Participant contacted to ascertain whether photographs taken. • Photographs collected from sufferer. (in person, through post, via email in case on digital photographs) • Photographs developed and examined by GG. • Photographs categorised into themes and numbered consecutively within these themes based on content of photograph (e.g. activities; hobbies, work etc; particular environments; holidays, home, etc) • Copy of narrative interview transcripts sent to participants for member checking.
4. Semi structured interview	• Semi structured interview conducted in participant's own home. Based on semi-structured interview methodology • Discussion of content of photographs with participant. Where, when, why photo was taken? What was going on in photo. What does photograph signify? • Follow up interview schedule – themes categorised into thematic areas based on lifeworld existentials. • Field notes recorded on tape immediately after interview and transcribed. • Semi structured interview transcribed ASAP after narrative interview.
5. Participant Pen Pictures	• Once both interviews have been conducted a 'pen picture' of the participant is written. Comprises of a general description of the participant, living circumstances, brief individual/family history, PD symptomology, presence of other health problems, and summary of main points of interview • Descriptions of contents of photographs written based on discussion in interview
6. Organising data using NVIVO	• Interviews, photographs and audio recordings entered into NVIVO.
7. In-depth thematic analysis	• In depth analysis of narrative and semi structured interviews. • Line by line coding of interviews. Themes arising from interviews entered into NVIVO database • Themes re-categorised into themes, sub-themes and categories. • Trees of categories and themes constructed. • Photographs selected as examples of particular themes. • Broad categories developed and formatted into separate word documents
8. Categorisation of thematic areas using lifeworld existentials	• Word documents examined and classified into four lifeworld existentials. • Lifeworld existentials used to structure findings chapters.
9. Analysis of content pertaining to ageing and gender	• Secondary analysis of categories and trees into issues relating to ageing and gender. • Separate chapter structures developed to record findings relating to ageing and gender identity.

Appendix 3.2 Narrative Interview Schedule

Initial narrative question.

The initial narrative question seeks to gain an in-depth description of the person's life story. The goal of this study is to focus upon experiences of PD, however such experiences cannot be removed from the person's wider life story. The goal of capturing an element of this wider life story is to contextualise experiences of PD within the individual's wider life story, so that PD experiences can be understood within the wider experiences of a person's life.

- ***In your own words, I would like you tell me about your general experiences of living with Parkinson's disease, and the problems that it has caused for you.*** *Please take as long as you like, I won't interrupt you while you are talking. Feel free to give me as much, or as little detail as you want to. After you have finished, I might also ask you to tell me about how having Parkinson's disease has affected some more specific areas of your life.*

Exmanent narrative questions.

Exmanent narrative questions (ie narrative questions related to specific research aims and objectives within this study) are based on the lifeworld existentials of lived time, lived body, lived space and lived relationality. Questions based on central research questions –aim to explore the lived experience and lifeworlds of men with PD. Issues relating to gender and ageing **will not** be explicitly asked within these narratives. However it is expected that much of the issues arising from narratives collected will relate to these issues. These issues will be explored more fully within a second qualitative interview which will be semi-structured in format. Areas for investigation in this interview will be determined after an initial analysis of data collected during the first interview.

Exmanent narrative questions are listed below. These questions will be translated into immanent narrative questions (ie grounded within individual experiences, and the verbal descriptions of these experiences during the initial narrative above) depending on the content of narratives from the initial narrative question asked above.

- Lived Time: ***Tell me about the events in your life leading up to, and after your diagnosis of PD.***
  (Past) after you first noticed something was wrong/ events leading up to diagnosis.
  (Past/present) events since being diagnosed with PD.
  (future) living with PD in the future.

- Lived Body: ***Can you tell me about the particular problems related to PD that you experience, and how they affect how you live your life.***
  (symptom experience) tell me about the PD symptoms you have (and how they affect your life).
  (embodied experience) tell me about how PD affects your body/affects you physically and mentally generally.

- Lived Space: ***Can you tell me about some of the day to day problems that you have as a result of your PD.***
  (lived experience) day to day experience of living with PD?
  (spatial experience) How does PD affect how you interact with the world around you? (Inside the home, outside the home)

- Lived Relationality: ***Does having PD affect the ways in which you interact with other people? Can you tell me about this?***
  (family) relationship with wife and family, children & grandchildren.
  (friends) relationships with friends
  (strangers) relationships with strangers.

Appendix 3.3. PROMS-PD participant summary document

General Information Pseudonym: Simon					
Study ID.	3013	Gender	Male	DoB	30/08/1957
Employment Status	other	Living status	Own house	Marital Status	married
Co habitation	Lives with 2 children	NS SEC code	1		
MMSE	30/30	ACE-R	98/100	CDR	0.0

Parkinson's Disease background			
Year of Diagnosis	2005	Years since diagnosis	4
Hoehn & Yahr	Unilateral disease	Schwab & England	80%
Current PD Medication	Rasagiline 1mg. 1.0 per day		
	Pramipexole 700ug 4.5 per day		

Movement & related symptoms					
Tremor	moderate	Dyskinesias	Yes	On-Off	Yes
Freezing	no	Speech impairment	Mildly affected	Sexual function	None
Facial masking	Slight hypomimia	walking	Mild difficulty	sleep	No difficulty

Mood/Cognitive/emotional problems					
Hallucinations	Yes	Tension	Present but not prominent	Forgetfulness	yes
Worries	Prominent but intermittent	Loneliness	Present but not prominent	general anxiety	Not present
Autonomic anxiety	Present but not prominent	Depression	Present but not prominent	Slowing	Present but not prominent
Fatigue	Present but not prominent	guilt/self worth	Not present		
Life satisfaction	poor	happiness	Not very happy		

Interview Summary Year 1

Patient exhibited major depressive symptoms, and was aware of this. Patient had been offered anti depressive medication, but chose not to be prescribed them. Patient used a variety of coping mechanisms for both depression and PD. Had wife living in residential care due to Alzheimer's disease, and was care for autistic stepson. Felt under stress due to these circumstances

Interview Summary year 2

Patient suffered from mild depression. Patient had a tendency to analyse his problems and impairments in great detail. He described this tendency as originating from caring for his autistic son. Patient also was caring for his wife, who suffered from early onset Alzheimer's and was currently living in a care home. Patient was stressed as a result of this. Patient was in the process of trying to sell his home to be nearer his wife, but was struggling to sell his house. This was causing extra stress

Interview summary year 3

Patient suffered from mid PD and had depressive symptoms. Patient felt that he was recovering from a period of depression, but was currently feeling stress regarding current life events, including a house move and renovations. Patient was awaiting the imminent death of his wife from advanced early onset Alzheimer's disease. Patient likened his recovery from depression as negotiating the rim of a bowl, only careful attention to his activities and moods stopped him from falling in. Patient felt he had improved physically, which he attributed this success to an exercise video game he had been using recently. 4/9/09 patients wife had died.

Appendix 3.4. Example section of a narrative data analysis template

thematic categories	main plot of narrative	Abstract	complicating action	evaluation	resolution	further interpretation in interview	own interpretation
bodily experience of symptoms	looking odd, looking like he's drunk	*(264-265) and the other one is that I'm less susceptible to that worry about appearing drunk and like a stumbling old idiot.*	*(265-267) Which is (3) is something I worry about when I trip over the pavement or (1) trip over my own foot or turn and bump into a doorway, that sort of thing.*	*(265-266) Erm, I know it appears, I do look a bit odd.*	*(269-271) So anything that can make me able to function more normally is a bonus, and the wii fit has had a positive effect on that.*		Worrying about his symptoms being on show. Fear of being judged to be drunk. Out of control of own body. Associated with being deviant. Being old. Looking for ways to deal with these symptoms – how his body looks to other people
bodily experience of symptoms	struggling with tiredness	*(287-288) Getting out and about isn't always the best way*	*(288-289) because it brings with it the fatigue and the tiredness of walking or, exercise,*				Tiredness. Fatigue coming on suddenly, result of activity but more so – caused by going out. Tiredness 'unnatural' – not connected to symptoms
bodily experience of symptoms	progression of tremor	*(1570-1573) Erm, the resting shakes have become more of a nuisance, the tremor has become more of a nuisance. The inability to function on a multi level like I used to is a real pain in the neck.*	*(1573-1574) Erm (5) apart from that I don't think its really progressed any great amount.*		*(1574-1575) I know if I didn't have the medicine I'd be in a hell of a state so.*		Tremor growing worse. Points towards deterioration of symptoms. Role of medicine. Tremor as a nuisance – interfering with activities. Functioning on multi-level – doing many things.

embodied activities and experiences	playing flight simulator games - escaping the PD	*(211-212) Well sometimes the only way to do that is to escape.*	*(212-215) And that can be through modelling, through flying my models or through flying on the computer, which as you know I fly flight simulators on the computer.*	*(215-218)And then apart from the fact that I'm a rotten pilot or that my hands shake a bit, I'm the same as anybody else. Through the medium of the computer you can be erm, confident and clear, (228-236). If you see the concept that through the computer and through the internet you can be one person, when you can escape if you like the bounds of who you really are, or what you really are. (2) So when I'm flying on the computer, I'm not free of Parkinson's, and increasingly its more apparent, because I have the head shakes and the hand shakes and tiredness in my arms and that sort of thing, but I'm able to, not compete really but erm, function on a similar level to the people that I'm in contact with.*	*218-219), because, behind the screen the other people can't see the broken wreck that's you.*	Game as a form of escape from body and its confines/limitations. In game not disabled – able to do things as well as previously. way of forgetting PD's symptoms for a time. PD interfering with this element of life – body movements affecting controlling game – showing Pd up to the self. PD can suddenly return, making him think about it.

Appendix 3.5. Example Thematic analysis of narrative categories

Lived body Narratives

3002	3013	3029	3068	3167
problems with walking	looking odd, looking like he's drunk	The difficulties of PD	Having less energy	Writing
walking and using a stick	struggling with tiredness	Not having enough energy	Turning over in bed	Struggling to write
bending down when gardening	progression of tremor	Sleeping problems	Going to the toilet. Difficulties with movement	Writing deteriorating
falling over	PD as all encompassing	Living with sleeping problems	Cutting food	Struggling to talk
carrying heavy objects around	PD always being there	Doing housework. Being idle	Slowing down	Feeling uncomfortable. Having to move around
feeling depressed	coping with the disease	meditation	Getting out of bed	Moving slowly. Feeling paranoid
feeling suicidal	analysing and learning from own experiences	Meditation and Parkinson's	Getting up off the toilet	Condition improving
depression and PD	looking for deterioration	Nervous breakdown – losing it while on holiday	Feeling tired	Dribbling
having nightmares	analysing deterioration	Feeling anxious	eating	Problems with toileting
being 80 years old	difficulty of fighting back	Dealing with doctors for anxiety	Shuffling	Struggling to deal with stressful situations
Carrying on with technical work and electrical work	losing focus and control over things	Feeling depressed	General problems with PD. Withdrawing from social activity	Not hiding away
forgetfulness	being calm and focused	Uncertainty over depression and PD	Losing interest	Stress and PD symptoms
problems with memory. Becoming forgetful	struggling to get on with things	Anxiety and PD interacting	Still going walking	Dealing with stress. Prevaricating
	sleeping and nightmares	Difference between depression and PD	Taking medication	Dyskinesia's and stress
	questioning whether problems are due to PD	Not being macho	Medication working	Not having cancer/ being grateful for small mercies
	dealing with excitement. Not doing too much	Driving a land rover	Medication wearing off	Struggling to multi task
	questions of ageing	Taking rasagiline		Period of not taking medication
	not giving up	Medication wearing off		Taking medication and losing power
	trying to understand the illness	Taking tablets		Forgetting to take medication
	playing flight simulator games - escaping the PD	Taking tablets and going out		Missing tablets
	playing wii fit - dealing with the PD	Meditation and PD medication		Dyskinesia's and medication
	having a go on a high ropes course. Dealing with excitement			Staying off tablets and hiding symptoms
	go karting - carrying on			
	giving up scuba diving.			
	taking medication			
	side effects of medication			
	medication regimes			
	taking the medication			
	thinking and concentrating			

3002	3013	3029	3068	3167
PD in the future	Being forewarned and forearmed	Treatment for Pd in the future – deep brain stimulation	Prospect of moving home	Getting a new land rover
Worrying about the future	Taking part in research	Future ageing	Having an aim to achieve	Worry about future at diagnosis
First noticing symptoms leading to diagnosis of PD	Understanding PD in the future	Making a decision about PD in the future	First coming across PD	Future - money
Feelings about the diagnosis	Feelings about future relationships	Suicide	Being diagnosed with PD	Dealing with Pd in the future
Good days and bad days	Likelihood of needing care in the future	Planning to end life	Good days and bad days	Being diagnosed
Having an off day	Finding motivation to the day	Progression of PD in the future	Going fishing	A stressful year – losing six months of illness
Struggling to repair electronic items	Having a new start	Working for BT – nervous breakdown	Feeling old and staying young	Keeping horizons open
	Having brighter horizons	Nervous breakdown – losing it while on holiday		Living on benefits
	Dealing with the diagnosis	Nervous breakdown – quitting work		
	Events leading up to diagnosis	Finishing work		Key
	Wasting bad days	Nervous breakdown – unemployment and incapacity		The future
	Having good days	Being diagnosed with PD		Diagnosis and the past
	Meaningless of days – the calendar	Having Pd for ten years		Fluctuations in time
	Finding things to do – making order in one's life	Feelings about having PD		Lived time in the present
	Procrastinating	Retirement and starting a new life		
	Sailing model yachts			
	Flying model planes			
	Thinking and living in the present.			

Lived Space

3002	3013	3029	3068	3167
Carrying objects from room to room	Dangers in the house	Redecorating the house	Using the bath	Feeling panicky in crowds
Life getting harder. Doing the washing up.	Coping with being distracted in the home	Moving house	Keeping house and garden clean	The world becoming too small
Doing DIY. Persevering with tasks	Going out	Going sailing/fishing	Prospect of moving home	Going abroad. Buying a house
Building a conservatory	Moving to new home	Going to a concert. Anxiety in crowds	Getting house ready. Making a decision	Driving around
PD affecting work	Moving to new home (2)	Going into hospital	Driving	Carrying on driving
Walking – becoming unsteady	Driving	Not liking crowds. Changing the character of the person	Going walking	Wanting to keep driving
driving	Walking on the great orme	Moving to ...		Driving fast
Forgetfulness when driving		Benefits of living in Nefyn		
		Going back to ...		
		Feelings about driving		
		Driving short distances		
		Walking two dogs		

Lived relationality

3002	3013	3029	3068	3167
Relationship with wife – living apart	Protecting family from PD	Splitting up with ex wife	Taking part in walking group - Delaying walks	Spending more time together with wife
Feelings about relationship with wife	Relationship with son	Depression among friends	Taking part in walking group - Asking for help	Relationship with wife
Choosing to not visit his son	Relationship with family after moving home	Friends attitude to depression	Taking part in walking group – not shaking	Relationship with children
Not looking forward to birthday party	Managing children's worry about Dad	Friends from Southport	Withdrawing from social activity	Working around other men
Being involved with PDS	Protecting the kids from PD	Friends and asking for help	Friendships and withdrawing	Struggling at a birthday party
Being neighbourly	Looking after family – stepson	Getting help from friends	Walking in a group – slowing group down. Feeling tired	Losing confidence. Covering up.
Looking after a neighbour	Looking after family – wife	Not hiding his PD	Staying involved in things	Going into crowds. Being brash
Looking out for neighbours	Bereavement	A different life. Changes to personality of person	Other people not appreciating person's difficulties	Public speaking. Bantering with people
Wanting a peaceful life	Communicating online with other people	Dealing with the doctors	Doctors knowledge and advice	Losing confidence in work. Dealing with workers
Modifying televisions for neighbours	Telling others about the PD	Dealing with mental health doctors		Changing his way of dealing with people
	Feelings about the future - relationships	Dealing with doctors – problems with receiving PD medication		Going into meetings
	Developing a social life	Being financially dependent on benefits		Dealing with an intruder.
	Concentrating on me			Being aggressive. Protecting self
	Giving something back to other people			Being alone
	Being calm and focused			Becoming introverted. Disliking crowds
	Controlling the PD around other people			Struggling financially
	Not hiding PD – being up front			Working for PDS
	Managing the doctor patient relationship with the consultant			Feeling hurt about TV show
	Developing the doctor patient relationship with GP's			Losing friends. Place in local community
	Taking part in research – feeling useful			
	Taking part in research – being seen to be useful			
	Being a member of the local community			

Lived Relationality

Photo narratives		
3002	3013	3029
Doing the garden	Going on the ropes course	Difficulties in looking after dogs
Pd and the garden	Effects of adrenaline	Rebuilding the beach hut
Losing the pleasure of gardening	Flying the seagull model	Owning a boat
A favourite tree	Building the seagull model	Launching boats
Neighbours azalea	Flying the seagull model (2)	Owning a land rover
Garden centre and plans for the garden	Modelling, escape and recovery	Struggling to drive the land rover
Fixing the shed	Forgetting about PD	Riding the motorcycle
Spending time in the garden	Modelling fine detail and forgetting PD	Medication problems
The hedge	Adventurous activities	New medication and riding the bike
Being confined to the garden	Freezing	Sense of medication working
Owning a classic car	Controlling the glider	Benefits of medication
Helping the neighbours	Making a spork	Walking in the local area
	Making a grab handle	Not wanting a blue badge
	Escaping from PD	Buying a land rover
	Modelling and escaping PD	Owning a motorcycle
	Being absorbed	Relaxing
	Flying and going to an airshow	Thoughts about his old home
	Banging into kitchen cupboards	Living a new section of his life
	Doing the bathroom	Walking the dogs
	Finding solutions to problems in physical space	A beach hut
	Cupboard doors	Owning a fishing boat
	Designing the bathroom	Riding to pwllheli
	Moving to Llandudno	Avoiding feeling trapped
	Going gliding	Loving the local area
	Welsh class	Not going on holidays
	Feeling safe in the area	Being loved by pets
	Helping others online	Having more dogs in the future
		Living without the dogs
		Socialising around the beach hut
		Going sailing with friends
		Going sailing alone